# DESIGNING USER-CENTERED INTERFACES TO SUPPORT CLINICAL DECISION-MAKING AND PATIENT ENGAGEMENT

A Dissertation
Presented to
The Academic Faculty

By
Hayley Evans

In Partial Fulfillment
Of the Requirements for the Degree
Doctor of Philosophy in the
School of Interactive Computing

Georgia Institute of Technology

November 2021

# DESIGNING USER-CENTERED INTERFACES TO SUPPORT CLINICAL DECISION-MAKING AND PATIENT ENGAGEMENT

Approved By:

Dr. Rosa Arriaga, Advisor
School of Interactive Computing
*Georgia Institute of Technology*

Dr. Gregory D. Abowd
School of Interactive Computing
*Georgia Institute of Technology &*
College of Engineering
*Northeastern University*

Dr. Betsy DiSalvo
School of Interactive Computing
*Georgia Institute of Technology*

Dr. Andrew Sherrill
Emory Psychiatry and Behavioral Sciences
*Emory University*

Dr. Eric Roland Kuhn
Standford Medicine, Psychiatry and
Behavioral Sciences
*Stanford University*

Date Approved:

# Acknowledgements

Without the support of my own circle of care, I could not have survived my PhD, produced these studies, and authored this dissertation.

First, thank you to my advisor, Rosa Arriaga. I knew from our first interaction that you were absolutely the type of strong person that I wanted to learn from (and you did not disappoint!). Thank you for supporting my many interests throughout my PhD journey from trying different research methods to exploring a wide range of topics. I am so fortunate to have had you to guide me through, pushing me to think about why something matters, approaching problems with strategy and pragmatism, and finding the 'holes' in my logic and writing to make me a better researcher. Not only that, but through every hurdle I have faced in my PhD, you have had my back. Most recently and notably, your continued support of my degree remotely from Buffalo after the birth of my first child. We so appreciate it and your willingness to have him join our meetings on occasion! I will always be grateful for your mentorship.

To my committee members, thank you for your time, support, and feedback. Given that much of this work occurred during the COVID-19 pandemic, I am especially grateful for your flexibility in accepting my adjusted my research plans. Gregory, thank you for being a great mentor in the lab, on previous projects, and as a member of my committee. Coming from the world of communications before graduate school, I have found that I am often able to 'razzle dazzle' my audience with my flashy presentations and upholding extreme confidence in speaking and body language. Thank you for being someone that this has never worked on once. I learned year one that getting a PhD meant I had better know what I was talking about and have the data to back it up! Betsy, thank you so very much for your mentorship in qualitative methods. I learned so much being your teaching assistant and am so grateful for the perspective you bring to this work. You were also such a huge support during my pregnancy and offered many words of wisdom and encouragement. Thank you, Andrew, for being part of the Prolonged Exposure Sensing System (PECSS) project since the beginning. It has been a pleasure to collaborate with you on many PECSS-related designs and research projects. Your insights have been invaluable and without you this work would not have been possible. Eric, I have already learned so much from you. Thank you for the insightful conversations and pushing my work even further. I am so appreciative of your perspective and support of this work.

Thank you to my Georgia Tech cohort members, classmates, colleagues, faculty members, and students. I appreciated the opportunity to learn with and from you all. There are far too many individuals to name everyone. Special thanks to Udaya Lakshmi, Marissa Keech, and Jung Wook Park for being wonderful research partners and dear friends throughout my time at Georgia Tech. Thank you to my co-authors Jiawei Zhou, Michaelanne Thomas, Marisol Villacres-Wong, Daniel Castro, Catherine Deeter, Theresa Hsieh, Kenneth Akers, Hue Watson, Azra Isamil, Irene Lopez Carron, Robin Quillivic, Elaine Shertz, Ashok Krishna, Danielle Schechter, Neha Kumar, Eric Gilbert, and Amy Bruckman. Many thanks to Sarah Liu who provided critical support on my dissertation work.

To my family and friends outside of Georgia Tech, I cannot express my gratitude. To my husband, Joe, thank you for supporting my every dream and decision to uproot our lives. Your sense of humor, heavy handed wine pours, superb coffee making skills, and willingness to go pick up really good takeout has powered my graduate school journey. I love you. To my parents, thank you for many trips down to Atlanta to watch my inner-city farm and more recently, for countless hours of free babysitting to allow me to conduct my research and write this dissertation. Without you, I would be a grad school dropout. I love you both. Thank you. To my sister, Autumn, thank you for your unparalleled editing and stenography skills and your ability to make me laugh on bad days. Finally, to my dear friends at Yongsa Martial Arts, Aglanta, and Buckhead Gymnastics, thank you for your friendship and making Atlanta feel like home.

Lastly, thank you to the National Science Foundation for funding this work and giving the PECSS project a chance.

# Table of Contents

# List of Tables

# List of Figures

# List of Abbreviations

| Full Form | Abbreviation |
|---|---|
| Clinician | C |
| Cognitive Behavioral Therapy | CBT |
| Civilian Trusted Other | CT |
| Diagnostics and Statiscal manual of Mental Disorders V | DSM-V |
| Electronic Heath Record | EHR |
| Emotional Processing Theory | EPT |
| Ecological Systems Theory | EST |
| Galvanic Skin Response | GSR |
| Human Computer Interaction | HCI |
| Posttraumatic Stress Disorder Checklist 5 | PCL-5 |
| Prolonged Exposure Therapy | PE |
| Prolonged Exposure Collective Sensing System | PECSS |
| Patient Engagement Quotient | PEQ |
| Patient Health Questionnaire 9 | PHQ-9 |
| Posttraumtic Stress Disorder | PTSD |
| Subjective Unit of Distress | SUD |
| System Usability Scale | SUS |
| Trusted Other | T |
| Traumatic Brain Injury | TBI |
| United States | US |
| Veteran | V |
| Virtual Reality | VR |
| Veteran Trusted Other | VT |

# Summary

The delivery of most psychotherapies has been constrained by data collected from patient self-report and clinician intuition for the last century. Clinicians who use evidence-based treatments need methods, tools, and data to efficiently track, assess, and respond to mental health needs throughout the treatment process. Patients need tools that provide feedback to optimize their therapeutic exercises and increase engagement. In this dissertation, I explore how interfaces shared by clinicians and patients can be used to support this aim in the context of prolonged exposure (PE) therapy, an evidence-based treatment used in treating post-traumatic stress disorder (PTSD). I focus on the case of designing for United States (US) veterans as well as the clinicians who treat them as US Veterans are disproportionately affected by PTSD due to the nature of their work.

In this dissertation, I investigate how to design shared, user-centered interfaces which seek to support clinical decision-making and patient engagement in the context of veterans with post-traumatic stress disorder (PTSD). To lay the groundwork for design, I detail the care ecologies of veterans with PTSD, identifying the human and non-human intermediaries involved in their circles of care as well as barriers to care and future design opportunities. Leveraging this information, I explore how a clinician dashboard for PTSD, sensor-captured patient generated data, and feedback gathered via text message from trusted others (e.g., friends, family) can be designed into a shared interface and support clinical decision-making and/or patient engagement.

# Chapter 1: Introduction

For the last century, the delivery of nearly all psychotherapies has been constrained by data collected from patient self-report and clinician intuition. This data is subjective and narrow, functioning as an ever-present obstacle in the practice, training, and delivery of psychotherapy. Clinicians who treat mental illness are in urgent need of methods, tools, and data to efficiently track, assess, and respond to mental health needs throughout the treatment process. Patients need tools that provide feedback to optimize their therapeutic exercises. My research proposes transforming mental health assessment and care through enhancing these clinical practices with data-driven approaches. This change requires new forms of automated and personalized data analysis and innovation in the fields of data collection and engaging user interfaces.

While this work is relevant to chronic care more broadly, I constrain my work to a specific population in great need of science-based clinical innovations: United States military veterans diagnosed with posttraumatic stress disorder (PTSD) [125]. Approximately 20% of veterans of the conflicts in Iraq and Afghanistan meet diagnostic criteria for PTSD [3,25]. PTSD is a trauma- and stressor-related disorder defined by the following symptom clusters: 1) trauma re-experiencing (e.g., intrusive memories and nightmares of the traumatic event); 2) avoidance of trauma-related situations, thoughts, and feelings; 3) negative alterations in thoughts and mood; and 4) hyperarousal [173]. PTSD has many comorbidities, including substance abuse [44,161,182], domestic violence [69] suicidal ideation [21,40,53,72], and medical illnesses [45,184]. PTSD is a chronic condition marked by considerable distress and dysfunction [173]. Fortunately, evidence-based treatments exist for PTSD. Among the many pharmacological and psychotherapy approaches that have been used to treat PTSD, Prolonged Exposure (PE) therapy[64] has the best evidence for therapeutic efficacy [31,79]. Unfortunately, access and utilization of PE is low [42,132]. One aspect of high-quality PE implementation is its significant volume of data exchanged between the clinician and the patient about therapeutic exercise engagement. These exercises include: 1) *in-vivo exposure* to real-world stimuli and situations that the patient usually avoids; and 2) *imaginal exposure* via the patient's narrative of their distressing trauma memories.

In recent years, clinical psychologists and computer scientists have collaborated to develop a variety of applications (e.g., mobile applications, teletherapy, virtual reality, etc.) that are designed to improve patient engagement, information gathering, and treatment delivery of psychotherapies for PTSD, including PE [10,179]. However, they have not yet leveraged modern computing capabilities to address the most critical shortcomings of psychotherapy in general and PE. They do not provide concrete information about patient engagement, including factors such as the presence of distractions and unnecessary physical movement, objective measures of distress, and other ecological factors such as location and interactions with other people. They do not help clinicians identify and respond to "clinician barriers" (e.g., inaccurately intuiting that the patient is either under-engaged or over-engaged). They fail to provide interfaces where both the clinician and patient can reflect on the current progress and make decisions about the therapy.

To address these areas of opportunity, I designed a set of research studies that would allow me to explore how a shared user interface might be designed to support both patient engagement and clinical decision-making. To do so, I characterized how we can conceptualize a veteran's circle of care, highlighting the roles of human (e.g., clinician, spouse) and non-human (e.g., mobile applications, electronic health records) intermediaries and identifying barriers and opportunities to care. Then, building upon this knowledge, I explore how a clinician dashboard for PTSD, sensor-captured patient generated data, and feedback gathered via text message from trusted others (e.g., friends, family) can be designed into a shared interface and support clinical decision-making and/or patient engagement. I test the hypothesis: "Designing user-centered interfaces for veteran care ecologies can support clinical decision-making and patient engagement during therapy for PTSD."

Through this research, I advance the field's understanding of how novel data sources can be built into shared interfaces for chronic conditions in mental healthcare and what implications this has for patient engagement, clinical decision-making, the dyadic patient-clinician relationship. My research addresses the following questions:

**R1: How do we characterize veterans' care ecologies as they undergo clinical treatment for PTSD?** Recently, there has been an increase in the HCI community's focus on designing for veterans with PTSD. However, few have documented the existing sociotechnical infrastructure of veterans while participating in clinical therapy for PTSD. In Chapter 3, I explain this sociotechnical infrastructure from the points of view of clinicians, veterans with PTSD, and friends and family members of veterans with PTSD, herein referred to as *trusted others.*

*Table 1: Summary of Research Studies*

| STUDY | DATES | DATA | RESEARCH QUESTIONS |
|---|---|---|---|
| ***Completed Studies*** | | | |
| **Study 1:** Understanding the Care Ecologies of Veterans with PTSD | May 2017-December 2019 | N= 21 (10 clinicians, 5 veterans, 6 trusted others); semi-structured interviews | • What are the formal and informal care partnerships surrounding a veteran as they undergo clinical treatment for PTSD?<br>• What technologies are currently used to support various stakeholders (veterans, clinicians, trusted others) during clinical treatment?<br>• How does the military identity impact the therapy process?<br>• How can the inclusion of other perspectives (trusted others, wearables, etc.) inform and impact clinical treatment? |
| **Study 2:** Steps Toward Designing a Clinician-Facing Dashboard for PTSD | August 2018 - May 2019 | N= 12 clinicians; Semi-structured interviews and N= 5 clinicians; feedback sessions | • What is the current intensive outpatient (IOP) process for preparing to see patients?<br>• What are the current limitations to patient-clinician interaction during therapy?<br>• Is the inclusion of trusted others a valuable goal? |
| **Study 3:** Using Sensor-Captured Patient-Generated Data to Support Clinician Intuition and Patient Self-Report in PTSD Therapy | January 2019 – June 2021 | N= 10 clinicians; think aloud sessions and system usability survey (SUS) | • How can we design an interface using sensor-captured patient-generated data (sPGD) to inform clinicians about patient engagement during therapeutic exercises?<br>• How will clinicians perceive the PEQ's utility and usability?<br>• How can PEQ be used to support clinical workflow and patient engagement? |
| **Study 4 :** Perspectives on Integrating Trusted Other Feedback in Therapy for Veterans with PTSD | September 2020 – June 2021 | N = 10 clinicians, N= 10 veterans with PTSD, N= 8 trusted others, N= 2 veterans with PTSD who are also trusted others; storyboard feedback, semi-structured interviews, survey | • What are ideal feedback text experiences as veterans progress through clinical treatment for PTSD from each participant group's perspective?<br>• How can we design the Social Sensing System with these findings in mind?<br>• How will participant groups perceive the Social Sensing System will affect patient engagement and clinical decision-making? |

**R2: What role can human and non-human intermediaries play in supporting patient engagement and clinical decision-making during clinical therapy for veterans with PTSD?** Recent work has explored the inclusion of human (e.g., self-report collected via mobile applications such as PE Coach) and non-human (e.g., biometrics) into care for veterans with PTSD.

However, none have yet examined how the inclusion of these perspectives could be used to directly measure patient engagement during clinical therapy. In Chapters 5 and 6, I explore how sensor-captured patient-generated data and trusted other feedback could be used in the clinical therapeutic context, respectively.

**R3: What elements of design are essential for shared, user-centered interfaces which seek to support clinical decision-making and patient engagement in the context of veterans with PTSD?** Most interfaces that support clinical therapeutic activities have been designed for either patients *or* clinicians. In Chapters 3, 4, 5, and 6 I unpack what future interfaces should consider in designing for both parties, and how these features support patient engagement and clinical decision-making.

A summary of each study including dates, methods, and research questions are presented below (*See Table 1*).

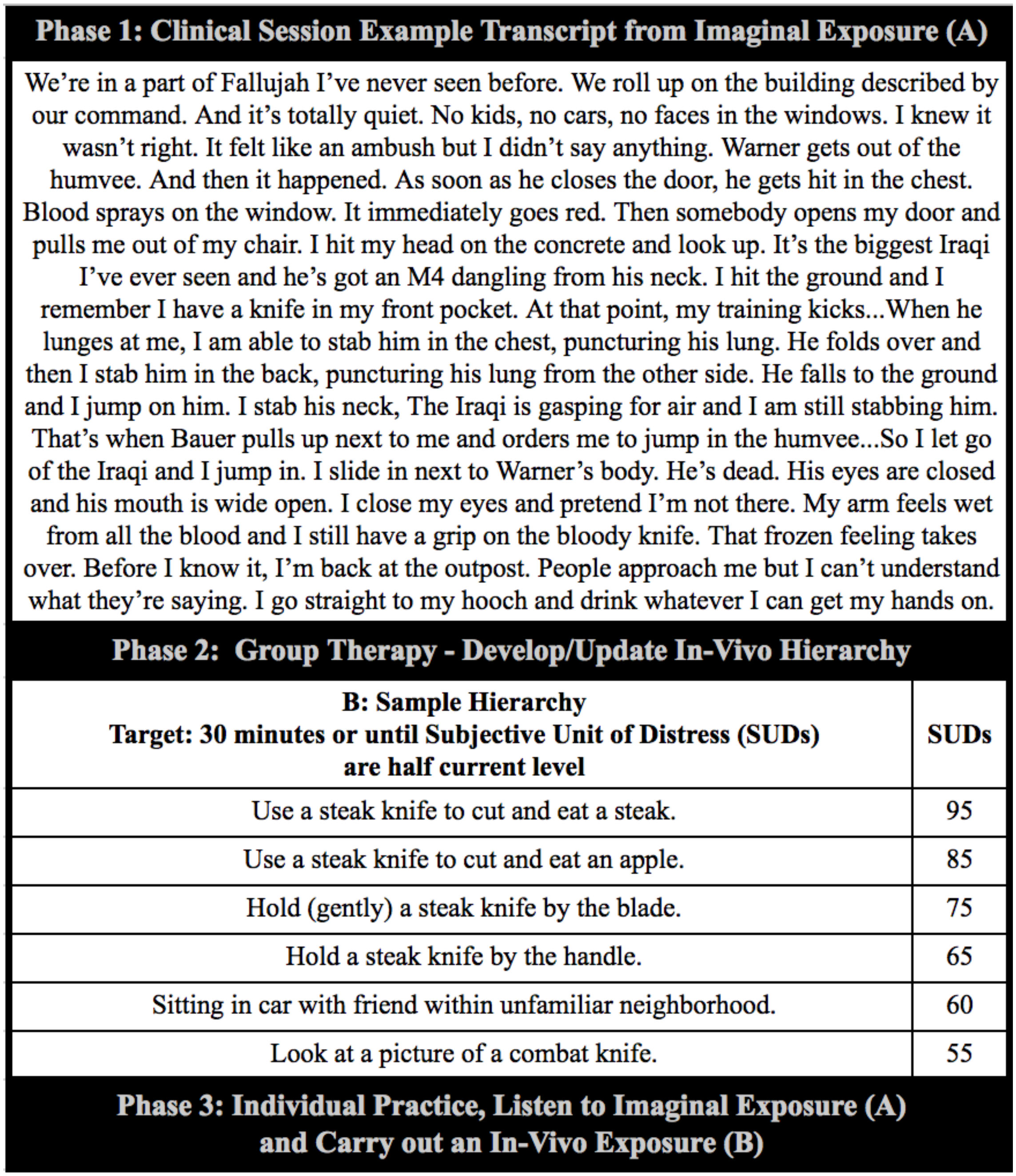
## 1.1 Posttraumatic Stress Disorder Treatment in Veterans

Posttraumatic stress disorder (PTSD) is a trauma- and stressor-related disorder characterized by trauma re-experiencing (e.g., intrusive memories and nightmares); avoidance of trauma-related situations, thoughts, and feelings; negative alterations in thoughts and mood; and hyper-arousal [44]. PTSD is a chronic condition marked by considerable distress and dysfunction with many comorbidities, including substance abuse [182], domestic violence [170], suicidal ideation, and medical illnesses [64,79,140]. US veterans are disproportionately affected by PTSD as compared to the US population, 16 percent to 6 percent respectively [45]. Approximately 20 percent of veterans of the conflicts in Iraq and Afghanistan meet diagnostic criteria for PTSD [25].

Recovery from PTSD is possible, but treatment entails an intensive process. Veterans must revisit and engage with traumatic events. Prolonged exposure (PE) therapy [133] and cognitive behavioral therapy are commonly utilized to treat PTSD in veterans. These therapies are delivered by clinicians through outpatient, intensive outpatient, and inpatient programs. They require guided work in the clinical setting as well as homework assignments in real-world contexts. Despite the proven effectiveness of several pharmacological and psycho-therapeutic approaches that have been used to treat PTSD [133,180], yet, only 50 percent of veterans with PTSD seek care [179] and the treatment dropout rate can be as high as 68% [49,50]. The treatment with the best evidence for therapeutic efficacy is prolonged exposure (PE) therapy [10,133]. PE therapy is delivered by clinicians through outpatient, intensive outpatient, and inpatient programs and requires guided work in the clinical setting as well as homework assignments in real-world contexts. Unfortunately, access to and utilization of PE is low [131,148]. One aspect of high-quality PE implementation is the significant volume of data exchanged between the clinician and the patient about therapeutic exercise engagement. These exercises include: 1) in-vivo exposure to real-world stimuli and situations that the patient usually avoids; and 2) imaginal exposure via the patient's narrative of their distressing trauma memories. These will be discussed in further detail in the next section.

## 1.2 Mental Healthcare Partnership and Setting

All research described in this dissertation was conducted in partnership with the Emory Healthcare Veteran's Program. Studies 2 and 3 specifically focus on designing in the context of the Intensive Outpatient Program (IOP) where clinicians practice exposure (PE) therapy. IOP uses repeated imaginal exposures and in-vivo exposures to activate and modify trauma-related fear structures to break the cycle of fear activation and avoidance. Fear structures are programs in one's memory that includes fear stimuli, responses, and meaning associated with both. Through imaginal exposure patients revisit the memories of the traumatic event by recounting them aloud in vivid detail with the clinician and then, between sessions, listening to recordings of the most recent session's recounting (i.e., practice, see *Figure 1, Phase 1*). Through in-vivo exposure practice, patients engage with real-world stimuli and situations that have become associated with the trauma memory and which the patient typically avoids reducing the negative affect associated with the avoided situation (see *Figure 1, Phase 2*).



**Phase 1: Clinical Session Example Transcript from Imaginal Exposure (A)**

We're in a part of Fallujah I've never seen before. We roll up on the building described by our command. And it's totally quiet. No kids, no cars, no faces in the windows. I knew it wasn't right. It felt like an ambush but I didn't say anything. Warner gets out of the humvee. And then it happened. As soon as he closes the door, he gets hit in the chest. Blood sprays on the window. It immediately goes red. Then somebody opens my door and pulls me out of my chair. I hit my head on the concrete and look up. It's the biggest Iraqi I've ever seen and he's got an M4 dangling from his neck. I hit the ground and I remember I have a knife in my front pocket. At that point, my training kicks...When he lunges at me, I am able to stab him in the chest, puncturing his lung. He folds over and then I stab him in the back, puncturing his lung from the other side. He falls to the ground and I jump on him. I stab his neck, The Iraqi is gasping for air and I am still stabbing him. That's when Bauer pulls up next to me and orders me to jump in the humvee...So I let go of the Iraqi and I jump in. I slide in next to Warner's body. He's dead. His eyes are closed and his mouth is wide open. I close my eyes and pretend I'm not there. My arm feels wet from all the blood and I still have a grip on the bloody knife. That frozen feeling takes over. Before I know it, I'm back at the outpost. People approach me but I can't understand what they're saying. I go straight to my hooch and drink whatever I can get my hands on.

**Phase 2: Group Therapy - Develop/Update In-Vivo Hierarchy**

| **B: Sample Hierarchy**<br>**Target: 30 minutes or until Subjective Unit of Distress (SUDs) are half current level** | **SUDs** |
|---|---|
| Use a steak knife to cut and eat a steak. | 95 |
| Use a steak knife to cut and eat an apple. | 85 |
| Hold (gently) a steak knife by the blade. | 75 |
| Hold a steak knife by the handle. | 65 |
| Sitting in car with friend within unfamiliar neighborhood. | 60 |
| Look at a picture of a combat knife. | 55 |

**Phase 3: Individual Practice, Listen to Imaginal Exposure (A) and Carry out an In-Vivo Exposure (B)**

*Figure 1: Description of IOP Therapy*

Veterans come to Emory for a 2-week period. On the first day veterans are introduced to the PE Therapy process, for example the meaning of the "subjective units of distress" (SUDs). On this day they are assigned to a cohort and to a specific clinician that they stay with for the duration of the IOP. During the next 9 days veterans are on a fixed daily schedule that includes one-on-one PE therapy with the clinician, group therapy, and individual PE practice. Phase 1 occurs in the morning and consists of an individual therapeutic session during which the patient revisits the traumatic event through imaginal exposure with the clinician (*see Figure 1, Phase 1*). Phase 2 is a group therapy session where the veteran meets with his/her cohort and a group leader. During this time, the group leader reviews the tenets of PE and helps each veteran develop and refine their individualized in-vivo hierarchy (*see Figure 1, Phase 2*). While Phases 1 and 2 occur in the clinical setting, and Phase 3 typically occurs outside the clinical office setting. Patients are expected to listen to the recording of the morning's imaginal exposure and complete one of the in-vivo exposure exercises (*see Figure 1*). Patients are expected to record their SUDs during each imaginal and in-vivo practice. Specifically, they are instructed to record their SUDs rating before the exposure and after the exposure, and the peak level.

### 1.3 The Cyclical Relationship of Patient Engagement and Clinical-Decisioning Making

While the term patient engagement is widely used in physical, mental health, and digital health research, there is no agreed upon definition. Several recent studies have attempted to analyze large bodies of literature to identify key characteristics and propose a unified definition of patient engagement [8,9,11]. An analysis of literature in health disciplines by Higgins *et. al.* led the authors to define patient engagement as the desire and capability to choose to participate in one's own care in a way that is appropriate for the patient, in partnership with a clinician or larger institution, with the goal of enhancing the experience and outcome of care. They identify personalization of care, access to resources, commitment to quality of care, and nurturing the therapeutic relationship as key attributes of patient engagement.

In narrowing the scope of defining patient engagement in the context of digital mental health in human-computer interaction (HCI), studies generally emphasize patient-centered care that results in enhanced health outcomes but may have varying focus on personalization [80], patient empowerment or agency to make decisions in their own care[9,20,37,208], adherence to the clinical protocol [172], and engagement with the technology itself [135,184]. Unsurprisingly, there is limited agreement in what characteristics constitute patient engagement in digital health interventions (DHIs). A 2019 meta-analysis by Ng *et. al.* examined how 40 evaluative digital mental health application studies measured indicators of patient engagement and found that no two studies used the same combination of subjective or objective criteria to assess engagement in the mental health applications [114].

Given the lack of consistency in defining patient engagement for DHIs, it is unsurprising that they have been the subject of criticism. They may be positioned as the sole catalyst for engagement and recovery, failing to acknowledge the complex sociotechnical environment (e.g., clinician-patient relationship, patient relationship with caregivers, cultural contexts, etc.) in which they are positioned [77]. Similarly, they may fail to acknowledge the nuances in a patient's ability or need to engage and how that might appear in technology. This may be especially true in the case of mental health. Torous et. al., explain that for individuals with more severe symptoms of mental illness, simply logging in to a DHI and performing one action may indicate a high-level of engagement whereas for those with less severe symptoms this may not constitute engagement [158]. Furthermore, in DHIs that provide patient resources, these may not all be equally relevant to different categories of patients. However, even when considering engagement in patient segments, this approach has been considered somewhat rudimentary and unsophisticated [7,63].

Generating a synthesized definition of patient engagement for DHIs or HCI is beyond the scope of this dissertation. However, it is essential to provide the context above and define what it is I mean when I refer to patient engagement. In this body of work, the definition of patient engagement draws on the work detailed above. Patient engagement combines a patient's knowledge, skills, ability, and willingness to manage their own health and care with interventions designed to increase activation and promote positive patient behavior [185]. The patient is situated at the center of care within a sociotechnical environment which must be accounted for in designing technology (e.g., clinician-patient relationship, patient relationship with caregivers, cultural contexts, etc.). Key characteristics of this view of patient engagement include personalization of care, access to data, and agency. Finally, patient engagement in the context of this work cannot be decoupled from clinician-patient relationship and subsequently, clinical decision-making. Patient engagement and clinical-decision making are viewed as an unending cycle throughout the course of treatment *(See Figure 2)*. For example, any data collected by patients during a therapeutic exercise will be shared with both patients and clinicians. Review of such data collected by technology can be used to support clinician understanding of patient performance in exercises, inform conversations between the patient and clinician, allow the clinician to tailor treatment to meet the needs of the patient, and provide space for patient agency and understanding of clinical treatment.

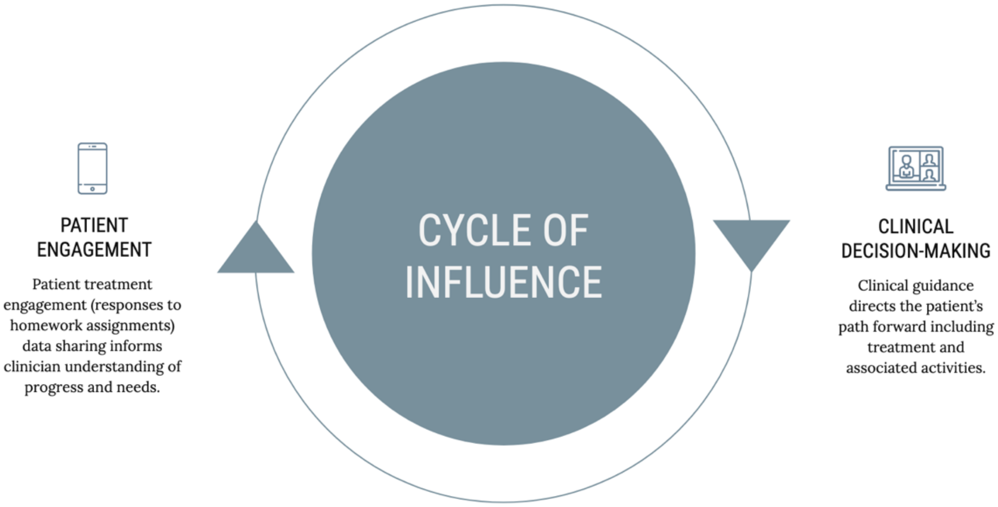


*Figure 2: The Cycle of Influence of Patient-Engagement and Clinical Decision-Making*

## 1.4 The Prolonged Exposure Collective Sensing System (PECSS)

The work in this dissertation is part of a larger effort to build the Prolonged Exposure Collective Sensing System (PECSS) with researchers at Georgia Institute of Technology, Emory University, and University of Rochester. In this section, I will describe the high-level purpose of the overall PECSS project and describe of the project aims which are relevant to the work in this dissertation.

PECSS aims to make fundamental contributions to the areas of sensor data analysis, human-computer interaction, and machine learning. In doing so it pushes the state-of-the-art in all three fields of computer science research. This will result in generalizable methods with a multitude of possible applications and thus impact beyond the field of mental health assessment and support. Equally important is the fact that this project aims to transform PTSD care. PECSS addresses the information gap between clinical sessions, enhances clinician and patient engagement, and supports clinical decision-making. The first contribution is the design of a computational assessment toolkit and novel interfaces that sit atop PE Coach. One PECSS team goal is to is redesign the patient facing application and design novel complementary clinician dashboards.

PE's premise is that symptoms will gradually diminish through repeated, systematic engagement with the trauma memory (imaginal exposure) and trauma reminders (in-vivo exposure). Avoidance behavior is at once an indicator of the distress level that the veteran is experiencing and at the same time an indicator of lack of engagement in the therapy. Therefore, a central PECSS innovation is our ability to provide the clinician objective information about "what was going on" while the veteran is inside or outside the clinic. Another contribution is the ability for PECSS to provide the patient tips about how to improve their practice, based on engagement data from previous practice sessions. A final contribution is an understanding of efficacy of the PE IOP itself. The PECSS team will process data streams through integrated modeling that aims to: *i)* automatically predict changes in *subjective units of distress scale (SUDs)* for each session; *ii)* unveil specific aspects and time-points of the therapy program that influence the overall progress and success of it for the *individual patient*; and *iii)* IOP level insights about what works in general and potential moderators and mediators of effectiveness. The latter can transform the IOP by providing insights into active treatment components and motivating refinement of the treatment model. This could streamline the IOP and make it more cost effective.

### 1.4.1 PECSS Aim 1: Development of ScapeSphere

The first aim of PECSS is to develop novel, user-tailored sensing systems that allow patient data transfer and information extraction during both imaginal and in-vivo exposure exercises. Passively collected objective data and subjective data captured during each patient's in-vivo and imaginal exposures can be used to calibrate participant engagement. For this reason, the team conceputalized *ScapeSphere*, a data collection system formed by four main components *LanguageScape*, *BodyScape*, *DigiScape,* and *SocialScape.* My work in Chapters 5 and 6 is situated within the development of the scapes listed below.

#### ***LanguageScape***

LanguageScape is a part of ScapeSphere that leverages natural language processing (NLP) based analysis of the imaginal exposure narrative. The goal of PE therapy is to decrease the distress associated with the trauma memory and reminders and to allow the patient to think about it differently. This goal is met through the imaginal exposure component of PE by having patients: 1) recount the traumatic event numerous times to learn that the memory is not dangerous; 2) build confidence that they can handle distress; and 3) gain a new perspective on the traumatic event via clinical guidance. This requires patients to provide a first-person narrative of the traumatic experience. While highly trained clinicians can encourage patients to recount their traumatic experience in sufficient detail to evoke short-term distress and thus drive habituation, there is limited data as to what language features are associated with effective imaginal narratives for PTSD. There is nascent literature on the role that psycholinguistics can play in understanding trauma memory [27], [30]–[33], but there have not been efforts to characterize how understanding this can lead the clinician to provide feedback about how the patient can improve their narrative. The PE treatment protocol encourages clinicians to correct the following examples of reduced quality for imaginal exposure: infrequent use of present tense, incomplete propositions, infrequent vocal power, infrequent sensory words, and infrequent use of emotion words [10]. An area ripe for exploration is using natural language processing (NLP) and machine learning to identify what constitutes "high quality" engagement in exposure exercises. PECSS will include an NLP feature which analyses patient language during the imaginal exposure exercises and provides feedback to both the patient and clinician to enhance treatment delivery and progression of the narratives over the course of treatment.

### ***BodyScape***

BodyScape is the part of ScapeSphere that leverages a commercial wearable (e.g., FitBit) to measure the body's physical reactions (e.g., heart rate). PTSD is characterized by distress that results from trauma re-experiencing (i.e., intrusive memories and upsetting reminders). However, heart rate has not yet been regularly incorporated into PE therapy sessions despite the existence of commercial products which have this measurement capability. We will leverage a commercial wearable such as a Fitbit into the PECSS framework and measure the efficacy of PE *imaginal exposure*. We will compare heart rate levels in the clinical setting and the natural environment.

### ***DigiScape***

DigiScape is the part of ScapeSphere that leverages the digital footprint of the patient. The emotionally evocative nature of imaginal and in-vivo exposure exercises leads some patients to engage in avoidance behavior during individual exposure exercises which are completed outside the clinical setting. Imaginal exposure exercises outside the clinic require that the patient listens to the narrative on their smartphone with headphones, while sitting quietly and without distractions. Currently, clinicians elicit self-report to assess the quality of each exposure session, but there is no objective measure to provide context and quality for the sessions. *DigiScape* will allow the team to examine the correlation between passive sensing data on a smartphone and the efficacy of therapy exercises. The PECSS team will capture data from patients' smartphones including but not limited to location, network connections, phone calls, and application usage. These features will also be investigated with a variation of SUDs levels and other contextual factors such as motion and ambient noise.

### ***SocialScape***

SocialScape is the portion of ScapeSphere that leverages a patient's social circle to provide additional information about their behavior outside the clinical office setting. Past research has shown that trusted informants are able to reliably report on the behavior of those with PTSD [54]-[55], however this approach has not yet been incorporated into PE practice. The team will bridge this gap in care and will collect information from trusted informants identified by the patient (expected to be a spouse or parent) via text message. Informant data is important because it provides corroborative information about a patient's therapy progression. Research suggests that approximately 80% of adults are willing to identify informants and to provide them consent to observe and rate their behavior for mental health purposes [57]-[58]. This is important because there are promising results from studies that use multiple informant perspectives for people suffering from PTSD. There is significant inter-rater reliability between veterans' self-report and informant ratings for pathology and distress in a PTSD therapy program [59]. Research has also found that spousal partners are able to acknowledge and estimate veterans' combat-related PTSD severity in terms of observable symptoms such as anger, anxiety [54], and avoidance [55]. However, informant perspectives from family and friends are rarely collected due to time, remembrance, and resource constraints. PECSS will bridge this gap.

### 1.4.2 PECSS Aim 2: Design of PECSS Interfaces

The PECSS team will design the PECSS Application and dashboard interfaces. These will serve two purposes. They will provide visualizations of various data streams (*LanguageScape*, *BodyScape*, *DigiScape,* and *SocialScape*) at the desired level of granularity for the patient via the application and for the clinicians via the dashboard. PECSS will also allow both the patient and clinician to receive specific information about current level of engagement and delivery, respectively. My work in Chapters 4, 5, and 6 builds towards this aim.

We know that patient self-tracking measures (e.g., SUDs ratings) have been found to facilitate better and more honest communication between a clinician and patient in consultations by providing concrete data about stress and behaviors [60]. However, for PECSS to deliver on its promise to transform PTSD treatment we will need to make sure that the interfaces are useful and useable. We will do this by using an iterative user-centered design approach. In Year 1 we will start the needs assessment phase and investigate which elements of the IOP are relevant to clinicians and veterans both individually and in a shared setting. Further, we will examine how and when these data points should be shared and when access should be granted to the patient or informants. In Year 2, we will take the information from Year 1 and build prototypes of the PECSS mobile app and dashboard complete with visualizations (to enhance the existing PE Coach application). We will also conduct usability testing. In Year 3 we will have a final PECSS design and will have built a robust system. It will include visualized information inferred and extracted by computational models. This will be evaluated with clinicians, patients, and informants.

## 1.5 Overview and Contributions

### 1.5.1 Contributions

Through four research studies I make contributions to field by exploring veterans' care ecologies, how human and non-human intermediaries can play a role in providing additional information regarding patient behavior during clinical therapy, and by designing a shared interface for clinicians and patients. There are relatively few patient- and clinician-facing interfaces to support clinical treatment of chronic mental illnesses. My research fills this gap by designing elements of both a mobile application for patients and dashboard for clinicians that display ecological data collected from sensor-captured patient generated data and trusted others. The design and presentation of this data will allow both parties to view these data streams at various levels of granularity, allowing both the patient and clinician to receive specific information about current level of engagement and treatment delivery, respectively.

Second, patient-clinician exchange of information between sessions in evidence-based therapies such as PE therapy is limited. My research aims to enhance this exchange of information by allowing for additional monitoring between appointments. Collecting and presenting additional data to both clinicians and patients through novel user-interfaces will impact patient education and support proactive and tailored care decisions made by clinicians. Furthermore, the current power dynamic between clinicians and patients is skewed heavily toward clinicians. While my research does not intend to equalize this balance of power and authority, it does seek to balance priorities and perspectives to create more open patient-clinician communication to improve clinician-decision making and patient engagement toward better health outcomes.

Third, evidence-based therapy is guided primarily by patient self-report and clinician intuition. However, this is not unique to PTSD. Presently, most evidence-based clinical treatments for chronic mental illnesses lack objective data collected between clinical sessions. This presents challenges in clinical decision-making as well as a patient's engagement and understanding of their own progress as most of the treatment occurs outside of the clinical setting (e.g., homework exercises). My research takes an ecological approach to designing user-centered interfaces to (1) illuminate both objective and subjective perspectives in both clinical and non-clinical settings which (2) can be utilized to design decision support tools that promote guidance of proper therapy practice and reflection on progress toward mental health management. This research will present information in the context of veterans with PTSD undergoing clinical treatment, however, many of the research and design implications may be applied more broadly to the treatment of chronic mental illnesses.

Finally, I describe how future work could formalize the approach I have taken in this dissertation by using Bronfenbrenner's Ecological Systems Theory (EST) [28] in combination with other feminist approaches such as Haraway [79,80] and Davis[45]. I describe how such an approach could be used beyond the realm of health for a broader design approach to assess current and future concepts.

### 1.5.2 Overview

This dissertation is organized as follows:

In Chapter 2, I detail related work that has served as the foundation for my research. I discuss the military culture's impact on veteran care, the cyclical relationship between patient engagement and clinical decision-making, what technology currently exists to support mental healthcare treatment for veterans with PTSD, and how human and non-human intermediaries provide insight to inform clinical treatment.

In Chapter 3, I explore veterans' care ecologies and lay the foundation for this dissertation. I identify both humans and non-human perspectives which are currently leveraged in some capacity as veterans undergo clinical treatment for PTSD. I also reflect on how this conceptualization fits within ecological systems theory and describe the Prolonged Exposure Collective Sensing system. The following chapters explore different areas relevant to this system.

In Chapter 4, I describe my early investigation into what a clinician dashboard could look like to support clinical decision-making using human and non-human intermediaries to inform care. This contributes towards the development of a PECSS clinician interface.

In Chapter 5, I describe the potential use of sensor-captured patient-generated data (sPGD) as a possible non-human source of information which can support patient engagement and clinical decision-making. I detail clinician perspectives on how this could be used in-session to inform clinical decision-making and patient performance and detail key design features of future system to support clinical decision-making for evidence-based therapies (e.g., exposure therapy). This research leverages BodyScape, DigiScape, and LanguageScape and contributes towards building a PECSS interface for clinicians.

In Chapter 6, I explore the use of trusted other feedback via text messages as an additional source of information regarding patient behavior in the real world and how that might be integrated into clinical treatment to support patient engagement and clinical decision making. I describe the perspectives of clinicians, veterans, and trusted others about their willingness and ability to use such a system and detail design implications. This research leverages SocialScape and contributes towards building a PECSS interface for both patients and clinicians.

In Chapter 7, I reflect on this body of work and summarize how these studies address the overarching research questions posed in this dissertation. I also reflect on the contributions of this work and highlight areas for future exploration.

# Chapter 2: Related Work

## 2.1 Technology for Trauma-Based Care

The shared interfaces I explore in this dissertation focus on evidence-based therapies in the context of trauma. Accordingly, it is important to review existing technology in the trauma-based care space, who it serves, and the efficacy for health outcomes.

A variety of technologies have been researched and developed for trauma-based care [130]. These technological innovations promise to reduce barriers to care such as PTSD-related avoidance symptoms, stigma, lack of proximal feedback and support, ambulation and transportation difficulties [108,153], and overall costs [75]. To date, most of these technological solutions for trauma-focused treatments have emphasized the patient experience and include internet-based treatments, virtual reality, and mHealth treatment and tools.

Internet-based or telehealth treatments are either standalone or supported. While standalone telehealth is highly scalable with small to moderate effect in reducing PTSD symptoms [83,149], the focus is usually limited to education and skills-training modules and attrition rates are higher than in-person [17,169]. At the same time, standalone telehealth cannot allow clinicians to monitor and address inadequate patient performance. On the other hand, supported telehealth are found to be more cost-effective than traditional in-person treatment [8]while not diminishing its effectiveness or increasing attrition [160]. Internet-based treatments have been developed to address patient engagement barriers, telehealth approaches (i.e., videoconferencing), standalone internet-based treatments, and supported internet-based treatments. Trauma-focused treatment delivered by a clinician via telehealth has been found to be more cost-effective than traditional in-person treatment [109] while not diminishing its effectiveness or increasing attrition [160]. Self-guided, standalone internet-based treatments are automated and highly scalable. These treatments include education and skills-training modules [17,169] and have small to moderate effect in reducing PTSD symptoms [83,149] while attrition rates are higher than in-person [17,169]. Through these treatments, it is not possible for clinicians to monitor and address inadequate patient performance. Lastly, interventions delivered through videoconferencing or email while virtual have patient engagement facilitated by a therapist. For example, a 2016 intervention developed by Littleton *et. al.*, the therapist contacts the patient via internet-enabled messages after each module [91]. Effect sizes for these treatments are somewhat higher than standalone internet-based treatments [83,149] and attrition rates are higher than in-person treatment [68].

Virtual reality has been used in trauma-focused treatments to help patients engage in therapeutic exposures to safe but avoided memories [147]. Specifically, while the patient is describing the traumatic memory, the therapist manipulates simulated environments to match the memory as it unfolds, thus making it easier for the patient to face the memory without avoidance. The efficacy of virtual reality exposure therapy has been found effective with veterans and civilians [34,53] and its effect on PTSD symptoms is like that of conventional exposure therapy [129]. Innovations in virtual reality are encouraging; however, research is needed regarding best practices with respect to facilitating patient performance, as it is unknown what are the critical characteristics of the simulations and protocols that lead to therapeutic change [146]. However, the costs associated with obtaining the appropriate hardware, software, and clinical training are currently prohibitive to most clinicians, thus limiting the scalability of virtual reality to enhance patient engagement [146]

MHealth applications have recently emerged as a more accessible means to enhance engagement in trauma-focused therapies. The most downloaded standalone app is PTSD Coach, which is presented as a tool to assist in PTSD management with information and learning coping tools [85]. The empirical evidence regarding its clinical utility is mixed and the observed effect on PTSD symptoms reduction is small compared to conventional in-person treatment [85,104,122]. Adjunctive apps are designed to help the patient engage in a conventional treatment where the therapist is tasked with monitoring and addressing patient engagement. The most downloaded adjunctive app for PTSD therapy is PE Coach [130], which has no clinician-facing version. It consolidates PE resources digitally in the patient's own smartphone with functionalities of therapy sessions recording, conduct in-app assessments, progress trackers, appointment reminders, and psychoeducation. While promising to make treatment activities more convenient, no trials have examined the effects of PE Coach on treatment outcomes. In addition, there is no clinician-facing version of PE Coach. Adjunctive apps remain an area ripe for innovation that goes beyond digitizing paper forms that can improve the patient's and therapist's ability to monitor engagement (e.g., multi-sensor systems) [37,138]. Available apps for PTSD treatment include standalone apps (i.e., self-contained programs with no therapist support) and adjunctive apps (i.e., complementary support for conventional therapy).

While several technologies have been created to support trauma-focused treatments, there are few interfaces created for both clinicians and patients [130]. Furthermore, little research has been done to provide tools for clinical decision-making for clinicians that face specific challenges based on their level of experience administering psychotherapies such as PE therapy [178]. For example, novice clinicians are may be overwhelmed by the manualized nature of PE therapy; they often focus on the implementation of in vivo and imaginal therapy and may forego key clinical skills such as listening. Successful PE therapy depends on patients fully engaging with their traumatic memories, and novice clinicians often fear that patients may over engage. Thus, even though PE therapy has high efficacy, its delivery can be improved.

My work expands this body of knowledge by presenting a shared, patient-clinician interface which examines patient performance in therapy from a variety of perspectives, what characteristics contribute to engagement, and how this data might be collected, displayed, and utilized in trauma-based therapies by clinicians and patients. I discuss this throughout chapters 3, 4, 5, and 6.

## 2.2 Partial, Caring Perspectives of Human and Non-Human Intermediaries

Haraway, among others, have underscored the need for including a variety of perspectives [58]. She argues these situated knowledges are disparate, rational, and incomplete but critical to constructing our understanding and are valid to varying degrees. These also compel us to question what we know (or do not know) by adopting a certain point of view and argues that we must strive toward understanding a variety of such perspectives. In this body of work, I explore how these partial perspectives can contribute toward creating a more holistic picture of veteran health as they undergo clinical therapy, and how these perspectives displayed through shared interfaces can support patient engagement and clinical decision-making.

I explore the inclusion of a human perspective from trusted others as veterans engage in clinical therapy. Afterall, caring for individuals with physical or mental health problems is a collaborative process [19] and involves human intermediaries. These are informal caregivers who support patients with some aspect of care [19,103]. They may be friends, family, or peers and have been shown to play crucial roles for supporting health outcomes [20] for a variety of conditions, including cancer [73], dementia[43], autism [65,81], and trauma[19]. The same is true for PTSD care. It involves the individual experiencing PTSD, clinical staff, and also other human and non-human intermediaries. Trusted others see the individual experiencing PTSD in real-world settings, understand their own experiences with the individual, identify actions to be taken [121], collaborate with the person receiving care [176], and aid in the overall health care of the individual [110].

Even clinicians are known to rely on reports from trusted others. In a recent study at a dementia care center, Foong *et. al.* explored non-expert, volunteer knowledge for dementia patients and found that clinicians believed the volunteers' knowledge was not only reliable but effective in resolving professional barriers such as bridging the gap between clinical language and lay language [43]. Previous studies have examined the inclusion of trusted others in clinical care for PTSD in veterans. One study acknowledged a significant correlation between veterans' self-report and observer ratings for pathology and distress in a PTSD therapy program [120]. Another found that spousal partners were able to acknowledge and estimate veterans' combat-related PTSD severity in terms of observable symptoms such as anger, anxiety [119], and avoidance [137]. However, as these informants may be directly impacted by the veterans' actions, they are likely to rate any observed problems at a higher rate of severity than clinicians [119]. Trusted informants are not as apt in identifying less obvious symptoms such as re-experiencing, hyperarousal [137], or intrusive thoughts unless the veteran verbally indicates their presence[119]. However, including the perspectives of trusted others involves negotiations, including managing burden [20,176], tool adoption, age accommodation, and acceptance of different roles for information sharing [117].

In addition to human intermediaries, there are also non-human intermediaries that play a role in supporting veterans' care. I also explore the inclusion of passive data (i.e., sensor-captured patient-generated data) to support patient engagement and clinical decision-making through a shared interface. This was motivated in large part because data from non-human intermediaries has already proven useful in the context of mental health. For example, machine learning analyses of electronic health records (EHR) [107] and Twitter data [15] have effectively predicted suicidality within PTSD samples. Biochip technology has been explored for more effectively diagnosing the stage and severity of PTSD [89]. Virtual reality has been employed to create realistic virtual environments for therapy sessions [129,147] and sensor-captured patient generated data has been used in the context of clinical mental health in veterans [112,113].

Haraway argues that non-human perspectives have a strong role to play in understanding identity and lived experiences [59].

Interestingly, Haraway makes no distinction between the roles of man and machine in her work. However, I believe in the context of this work it is essential that the balance of power be examined, otherwise unintended power dynamics [174] with the inclusion of additional perspectives may negatively affect patient engagement, clinical decision-making, and the patient-clinician relationship. Jenny Davis warns that it is essential to examine from whom designs afford and under what contexts [32]. It is crucial to question the appropriate balance of data access, the weight each perspective may have, and how the experience of each individual (e.g., novice vs. expert clinician) will affect patient engagement and clinical decision-making. My research builds on prior scholarship related to partial knowledges in complex healthcare ecologies [70] by examining the perspectives that both human and non-human intermediaries might contribute. I aim to understand the role these human and non-human relations play in support of the mental well-being of veterans with PTSD. I extend this knowledge by examining the inclusion of trusted other feedback and sensor-captured patient-generated data which can be displayed in shared interfaces as a veteran undergoes trauma-based treatment (e.g., PE therapy) for PTSD.

### 2.4 Designing Mental Health Interfaces in Stigmatized Contexts

HCI is increasingly concerned with enhancing therapy for mental illness by creating supportive technologies that emphasize patient engagement and call for a shift towards more democratic, patient-centered care practices [132]. This is especially critical in the realm of mental health which emphasizes the need for trust in the patient-doctor relationship, which gives rise to patient engagement (e.g., empowerment, agency) [43]. Technology has helped to facilitate this shift, providing means to support clinical treatment and encouraging patients to be active participants in their own mental healthcare [24,179]. The notion of patient engagement has been explored through a variety of mental health conditions [4,5,101] and technologies [113,156,159]. These supportive technologies emphasize the need for information sharing [113], visualization of treatment progress [24], customization [6,177], and eliciting patient reflections to place at the center of care [96,154]. This can be critical for condition management and collaborative sense-making in therapy [1].

Various design considerations have been noted, including a need for information sharing, visualization of treatment progress [16], and eliciting patient reflections to place at the center of care [95,97,155]. However, technologies focused on patient engagement have been criticized for neglecting individual needs [21,158] and even disempowering patients by placing too great an emphasis on treatment compliance [150]. Furthermore, inherent power dynamics in the clinician-patient relationship must be considered as any introduction of shared interfaces will affect the status quo [33,175].

Patient engagement may be especially difficult in stigmatized contexts [71]. Stigma occurs when a person is viewed in a negative way for a perceived or real quality (e.g., mental health condition) [24,39,52,116]. Individuals may stigmatize themselves through negative thoughts and emotions [30,136]. Stigma negatively characterizes the out group, which causes segregation between us and them. These views are common in Western society [30,136], and as a result, those with mental health conditions may be perceived as dangerous, unable to make their own decisions, and dependent on others [29,30,136]. Some people with mental health disorders avoid help-seeking behavior because they fear being stigmatized and discriminated against [62,136,141]. They may also believe they are not worthy of receiving clinical help, that treatment will not improve their condition or that seeking help from their social networks will be burdensome [29].

Previous research has examined how to empower stigmatized patients to seek and manage care through a variety of technologies. These may allow individuals to control the visibility of the condition [9] or build upon existing social behaviors and technologies to cope [36]. They may also incorporate the ideas and perspectives of stigmatized individuals into the design process. For example, Marcu et. al. utilized participatory design to empower HIV-positive youth to design a technology to improve medication adherence and fostered adoption and usage of an intuitive technology [98]. While some technology is designed to reduce the impact of stigma, all must appreciate the potential of further stigmatizing the population or exacerbating vulnerabilities [94,164].

The work of this dissertation focuses on designing for veterans with PTSD, who face a complex stigma due to their military culture and diagnosed mental illness. US veterans belong to a subculture of American society shaped by unique norms, conditions, and belief systems associated with the military [26,57,82]. They have a warrior mindset and collectivist identity

[26,126]. In adopting a warrior mindset, military personnel learn to value honor, fearlessness, restraint, and readiness for battle [57,126]. Embracing a collectivist identity allows military personnel to learn to prioritize the mission and well-being of the group over themselves [26,126,143]. Veteran identity is associated with attributes such as stoicism [143], denial of weakness or illness, and secrecy [171]. These attributes pose challenges in seeking care and support [26,143]. Veterans often dismiss their own reactions to trauma as a normal consequence to abnormal incidents from their military service [87,143].

Psychotherapies such as PE require veterans to re-engage with traumatic memories under clinical guidance [87]. However, some veterans are reticent to disclose mental health needs to civilian clinicians [26]. Other veterans may emote in a restrained manner to maintain their military identity [26,51]. Clinicians may also be faced with knowledge gaps due to a limited understanding of military culture [26,82]. These embedded barriers may lead veterans to engage support networks outside clinical settings [87].

Support networks are critical during stressful times. This is the case when veterans leave the military and must put their military identity aside. Veterans re-adjusting to civilian life may feel disconnected from their social groups [82,143]. To regain a sense of control, they reach out to fellow veterans on social media [22,143,144]. These online forums connect veterans to a familiar culture and have notable communication features that include disclosure strategies, self-censorship, judiciously sharing, and abstaining from posting to maintain individual anonymity [143].

My work extends this body of knowledge by examining how to design shared interfaces for veterans with PTSD and their clinicians during the process of trauma-based therapy for PTSD (e.g., PE therapy). I build upon these learnings and share design implications for future systems in Chapters 3, 4, 5, and 6.

# Chapter 3: Care Ecologies of Veterans with PTSD

## 3.1 Introduction and Related Work

Human-Computer Interaction (HCI) research increasingly targets improved provision and uptake of healthcare [40,107]. Much of this work occurs in large-scale clinical systems that require collaboration across multiple stakeholders from disparate backgrounds. This includes doctors, patients, families, and institutions, among others[56,70,105]. A growing focus emphasizes patient engagement, foregrounding patients' perspectives amid these complex ecologies of care. It also requires scrutiny of the various (human and non-human) intermediaries that play a role in facilitating care [7,56,103,105]. My first research study extends this scholarship to US military veterans with PTSD and acts as a foundation for the remainder of the dissertation.

In this chapter, I describe the care ecologies of veterans with PTSD. I describe the military identity these veterans share and how this may add to their reluctance in care-seeking behaviors. I also identify and describe the roles of human and non-human intermediaries in ecologies of care. I discuss how military culture can be utilized in clinical care, how multiple perspectives can be leveraged to create a more holistic view of the patient, and finally, how veterans can be empowered during treatment. I also share recommendations for the design of sociotechnical systems that prioritize the above in support of the mental well-being of veterans with PTSD.

My approach to this qualitative study was in large part influenced by Bronfenbrenner [18]who proposed that individuals are best understood when seen as being at the center of an ecological system. In his ecological systems theory (EST), human development is a complex system of relationships affected by various layers of the individual’s environment including immediate, community, societal, and environmental settings (*See Figure 3)*. While he never considered the role that technology could play in EST, this approach has acted as a framework that has guided my thinking around the types of data which can be collected at the various levels and can help us understand the ecological context of evidence-based treatment for veterans with PTSD. At the end of the chapter, I synthesize the findings of this study with EST to visually demonstrate the care ecology of a veteran with PTSD.

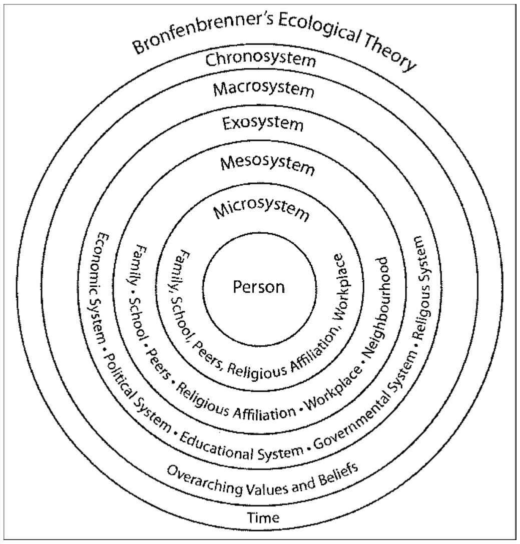


*Figure 3: Bronfenbrenner's Ecological Systems Theory*

In this study, I answer the following research questions:

- **RQ1:** What are the formal and informal care partnerships surrounding a veteran as they undergo clinical treatment for PTSD?
- **RQ2:** What technologies are currently used to support various stakeholders (veterans, clinicians, trusted others) during clinical treatment?
- **RQ3:** How does the military identity impact the therapy process?
- **RQ4:** How can the inclusion of other perspectives (trusted others, wearables, etc.) inform and impact clinical treatment?

### 3.2 Methods

All aspects of this research design were authorized by Georgia Institute of Technology's Institutional Review Board (IRB). Recruitment occurred through three primary means. First, I reached out to about 50 personal contacts associated with veterans, including veterans themselves, clinicians, and friends and family of veterans. I used snowball sampling to recruit additional participants. Second, I posted messages about the study on 75 social media channels, such as Reddit, NextDoor, and Facebook, to attract participants. Finally, I reached out to clinicians who worked with veterans through private messages via LinkedIn and email. In utilizing a market-model compensation scheme, clinicians were not compensated, but all other participants were entered into a $50 gift card raffle for their participation.

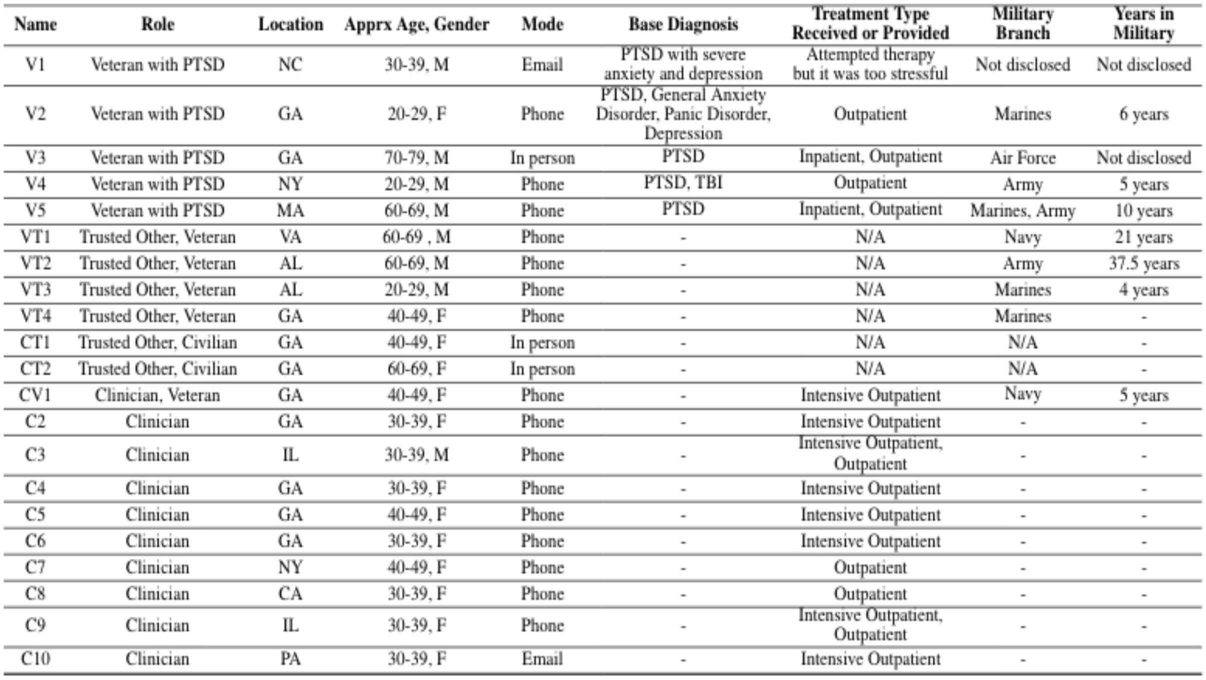
All participants provided signed consent via paper or electronic forms before proceeding with the study. I interviewed 21 participants, including 10 clinicians (C; one clinician is also a veteran and labeled CV), 5 veterans with PTSD (V), 4 veterans who are trusted others (VT), and 2 civilians who are trusted others (CT). No veteran or civilian participants had relationships with clinician participants. Two trusted others had relationships with two of the veterans with PTSD who participated in the study. Names of participants were changed to protect their identities. An additional 10 potential participants chose not to proceed after reading the IRB consent form (8 did not respond after receiving the form, while 2 explained that they were not inclined to sign a consent form).

All the clinicians interviewed had treated veterans with PTSD via the Veteran Administration (VA) and private institutions through outpatient and intensive outpatient programs. While most of the clinicians delivered therapy in-person within a clinical setting, one clinician provided in-home treatment, and another offered telehealth services. Clinicians were located throughout the United States. Additional details about the participants can be found in Table 2.

Among the veterans I interviewed, four identified as male and one as female. These individuals had served as enlisted members of the Army or Marines. All these individuals have received treatment for PTSD through inpatient and/or outpatient programs through a variety of institutions in various locations in the Northeastern and Southeastern United States.

Finally, I interviewed trusted others, who are friends or family members who act as caregivers to veterans with PTSD. This included four fellow military veterans and two civilians. The military veterans represented the Army, Air Force, Navy, and Marines. Each of these individuals has had relationships with veterans suffering from PTSD, in which they interacted with the person three or more times per week. One veteran was the mother of a veteran with PTSD, whereas another veteran participant had several friends who were veterans with PTSD. Two were military officers who are still involved in the veteran community. Both civilian-trusted others were women who had long-term romantic partnerships with veterans with PTSD.

*Table 2: Background Information on 21 Participants in Study 1*



| Name | Role | Location | Apprx Age, Gender | Mode | Base Diagnosis | Treatment Type Received or Provided | Military Branch | Years in Military |
|---|---|---|---|---|---|---|---|---|
| V1 | Veteran with PTSD | NC | 30-39, M | Email | PTSD with severe anxiety and depression | Attempted therapy but it was too stressful | Not disclosed | Not disclosed |
| V2 | Veteran with PTSD | GA | 20-29, F | Phone | PTSD, General Anxiety Disorder, Panic Disorder, Depression | Outpatient | Marines | 6 years |
| V3 | Veteran with PTSD | GA | 70-79, M | In person | PTSD | Inpatient, Outpatient | Air Force | Not disclosed |
| V4 | Veteran with PTSD | NY | 20-29, M | Phone | PTSD, TBI | Outpatient | Army | 5 years |
| V5 | Veteran with PTSD | MA | 60-69, M | Phone | PTSD | Inpatient, Outpatient | Marines, Army | 10 years |
| VT1 | Trusted Other, Veteran | VA | 60-69 , M | Phone | - | N/A | Navy | 21 years |
| VT2 | Trusted Other, Veteran | AL | 60-69, M | Phone | - | N/A | Army | 37.5 years |
| VT3 | Trusted Other, Veteran | AL | 20-29, M | Phone | - | N/A | Marines | 4 years |
| VT4 | Trusted Other, Veteran | GA | 40-49, F | Phone | - | N/A | Marines | - |
| CT1 | Trusted Other, Civilian | GA | 40-49, F | In person | - | N/A | N/A | - |
| CT2 | Trusted Other, Civilian | GA | 60-69, F | In person | - | N/A | N/A | - |
| CV1 | Clinician, Veteran | GA | 40-49, F | Phone | - | Intensive Outpatient | Navy | 5 years |
| C2 | Clinician | GA | 30-39, F | Phone | - | Intensive Outpatient | - | - |
| C3 | Clinician | IL | 30-39, M | Phone | - | Intensive Outpatient, Outpatient | - | - |
| C4 | Clinician | GA | 30-39, F | Phone | - | Intensive Outpatient | - | - |
| C5 | Clinician | GA | 40-49, F | Phone | - | Intensive Outpatient | - | - |
| C6 | Clinician | GA | 30-39, F | Phone | - | Intensive Outpatient | - | - |
| C7 | Clinician | NY | 40-49, F | Phone | - | Outpatient | - | - |
| C8 | Clinician | CA | 30-39, F | Phone | - | Outpatient | - | - |
| C9 | Clinician | IL | 30-39, F | Phone | - | Intensive Outpatient, Outpatient | - | - |
| C10 | Clinician | PA | 30-39, F | Email | - | Intensive Outpatient | - | - |

All semi-structured interviews were conducted over a period of 12 months. Interview questions focused on understanding the therapy experience, technology usage, data collection practices, involvement of trusted others, and ways participants believed technology could support the therapy experience for each stakeholder group. Questions in each category were tailored to veterans, trusted others, and clinicians. For example, when asking about trusted other involvement, veterans were asked about the nature of their relationships with trusted others and in what ways these individuals were involved, if at all, in their care. Trusted others were asked about the nature of their relationships with veterans and how they perceived their role in that veteran's care. Clinicians were asked about involving trusted others in their clinical practice.

Interviews lasted from 30 to 90 minutes, were recorded, and later transcribed. 2 were conducted in person, 15 over the phone, and 3 via email. Choice for interview format was based on participant preference, which reduced participant burden while also limiting selection bias. Despite the interview format, all participants answered the same set of questions (e.g., for veterans: ``What information do you provide to clinicians?", ``What technologies, if any, do you use to manage your condition?"). Email participants submitted written responses to these questions.

The interviews were analyzed using thematic analysis [16]. First, I conducted an inductive thematic coding analysis of relevant literature on themes of military culture, care-seeking, and patient empowerment highlighting the terms “Privacy,” “Veteran Identity,” and “Trusted Others in Treatment.” I worked with another PhD student to independently code the interview data from the bottom-up and developed a set of twenty axial codes across all participants. Using this initial code book, we again independently coded the interview transcripts from the top-down. The entire research team met to review, debate, and refine the code book. We defined five overarching themes derived from the initial twenty axial codes to explore care ecologies as well as the behaviors and interactions that affect participants during care interactions. These themes included care seeking, participation in care, treatment progression, trusted others’ opportunities, and future ideas for patient engagement and are referenced in the next section.

## 3.4 Findings

There are three main participant groups in the care ecology that will be referenced in this results section including civilian (CT) and veteran (VT) trusted others, veterans with PTSD (V), and civilian (C) and veteran (CV) clinicians. Veterans with PTSD offer perspectives on their care experience with emphasis on the roles of clinicians and trusted others in supporting such care. Trusted others provide insights on veteran behavior, as well as their own involvement in treatment. Finally, clinicians offer perspectives on their practices, the experience of treating veterans with PTSD, and the inclusion of trusted others in the clinical process.

### 3.4.1 Military Identity Shapes Care-Seeking Activity

Veterans are reticent to seek clinical attention for their mental health issues. In this section, I detail the impact of military identity both as a barrier to care and its significance in the clinician-veteran matching process.

#### *Veteran Military Identity Acts as Barrier to Care*

Military training brings veterans to adopt a military identity that favors hyper-masculine behaviors such as strength [26,27,143], stoicism [143], and secrecy [171] and poses challenges to seeking and receiving care [26,143]. Veterans assume this identity after they undergo training in a branch of the US military. They reflect an identity aligned to the culture of the specific military branch. It is not gender-specific and seeks to unify under a common identity, as VT4, a veteran-trusted other participant, detailed in her experience as a US Marine:

> *"You know how Christians can be born again? Well, we kind of feel like we're born again in the Marine Corps. It's a new you, it's a better you. When you become a Marine, you have a new family; you're born into this family, and you have brothers and sisters. We'll die for each other."* (VT4)

Clinicians, veterans, and trusted others explained that veterans often sought care after PTSD symptoms could no longer be ignored. V1 shared the experience that brought him to admit he had a problem:

> *"...my wife attempted to wake me very abruptly and I sent her to the hospital. As this was unintentional, I did see that my PTSD was so severe that I checked myself into the VA that day to get treatment."* (V1)

Other participants explained that military identities may discourage veterans from seeking care. VT1, a veteran-trusted other participant, shared the following experience. He was a contractor for the Department of Defense after the Gulf War, and his job was to encourage fellow veterans to enroll in health care treatment at the VA. He explained how difficult it could be to spur care-seeking behavior in veterans. He lamented the challenges he faced in his role:

> *"These veterans] weren't ready to admit anything, to get them to `fess up to having some kind of mental [health condition]... and get professional help. You couldn't get [them] to go to the hospital if they were physically ill. There is a culture that is built into the military: you will push on no matter what. You will not be a malingerer because you're part of a team and you never want to leave your teammates hanging."* (VT1)

### *Clinician Exposure to Military Culture Impacts Care*

Veterans face an additional challenge when seeking care based on their clinicians' understanding of military culture. Clinicians C7, C3, and CV1 emphasized the need for breaking down the hyper-masculine shield and connecting with other veterans to deliver effective treatment. C7 reported that a solid match leads to developing rapport and ultimately, allows the veteran to share experiences more openly with their clinician. V4, a veteran with PTSD, explained why it was easier to connect with another veteran rather than a civilian:

> *"You're not as open with personal problems, especially things that revolve around military service. Civilians don't have those experiences, backgrounds, and issues."* (V4)

These interviews illustrated further that a strong match between the clinician and the veteran-patient was critical not only at the initial stage but also for treatment adherence, engagement, and success. CV1, a clinician and veteran, said that because of a shared military identity, she was able to quickly overcome barriers many non-veteran clinicians faced in encouraging patient vulnerability. C3 suggested that clinicians may encourage vulnerability in veterans by demonstrating their success with veterans or veterans with attributes similar to the patient.

Despite the clear need for cohesive matching, mismatches between clinicians and veteran-patients are somewhat commonplace. Three veteran participants diagnosed with PTSD had experienced a poor pairing with a clinician at the VA. They explained that these clinicians had not taken time to listen or understand their background and experiences. This caused V2, V3, and V5 to stop receiving care for a period of time before seeking a new clinician at the VA or in the private sector. CT1, a civilian-trusted informant, said that her ex-boyfriend had also experienced a mismatch at the VA. He had not wished to be medicated and was marked as defiant:

> *"He didn't like that he was labeled volatile because… he didn't want to take medication for PTSD. They didn't offer him any other kind of therapy, like exposure therapy or anything like that. They just said, take medication… he decided not to finish [treatment]."* (CT1)

### 3.4.2 Human & Non-Human Intermediaries Inform Care Delivery

In this section, I share the limitations and opportunities of incorporating two types of partial perspectives in veteran care. First, I examine human intermediaries, including the current role of self-report data in clinical care, dependence on veteran-veteran networks both in treatment and their daily lives, and the importance of trusted others in providing real-world observations of veteran behavior to clinicians. Next, I describe clinician and patient technology used to understand the role of non-human intermediaries in PTSD care.

### *Veteran Self-Report: A Primary, Problematic, and Partial Data Source in PTSD Care*

Evidence-based PTSD therapies are reliant on veteran self-report[180]. For example, in session, veterans complete standardized assessments (e.g., PHQ-9, PCL-5, exposure-based homework assignments in which they record subjective units of distress (SUDs), and in-person exposure-based exercises alone or in a group under the guidance of clinicians [132]. Self-report is limited as it is inherently biased. As such, I have labeled veteran self-report as a 'human intermediary' as they may intentionally or unintentionally mediate what is reported during therapy and provide a particular perspective to the therapeutic context by doing so. The data show that self-report is particularly problematic for veterans with PTSD who are likely to also suffer from traumatic brain injury (TBI) [181]. V1 said:

> *"Unfortunately, with all of my stress from lack of sleep and anxiety, my memory tends to really be short-term."* (V1)

To improve recall, veterans in this study implemented strategies to record activities to share during clinical sessions. V4 and V2 were instructed to write down their nightmares by clinicians. Yet, they would only do this if they remembered or felt motivated. Four clinicians instructed their patients to use the PE Coach mobile application's [84] recording functions to track homework.

Clinicians utilize their intuition to navigate and extrapolate from veteran's self-report [180]. Clinicians explained that during therapy sessions, they probed veterans' experiences more deeply to better understand how veterans cope and manage their lives. They stated this is critical as veterans may over-report symptoms to receive government care or compensation, just as they may under-report to maintain a strong image and avoid stigma [151].

### *Fellow Military Veterans are Peer-Support Systems*

Veterans utilize veteran-veteran networks for support whilst in clinical therapy. Notably, this phenomenon of peer support via collective identity has also been identified in managing stigmatized illnesses in online communities [107]. Participants explained that this reliance was learned during their military service when they were expected to rely on one another for mental health support. Veteran-trusted others VT1, VT2, and VT4 said active-duty officers and enlisted ranks kept a close eye for aberrant behavior, and if the situation was serious enough, they willingly divulged information to officers or chaplains in order for that individual to receive appropriate care. VT4 said that this was critical as the hyper-masculine attitude of the military could prevent individuals from seeking out treatment. It is noteworthy that VT1 and VT2 both received formal mental health training during their service, while VT4 did not. VT2 described his readiness to care for a fellow veteran as such:

> *"We are trained to take care of one another, to watch each other's moods, to be sensitive to personal issues that are being raised, and to know of anything anybody was suffering from."* (VT2)

The experience of VT4 showcased the relevance of formalized training in health received in the military. However, regardless of formal or informal training received by veterans, there was a clear sense of interdependence among veterans interviewed, regardless of military branch and rank.

Veteran-participants relied on one another for mental health support while in clinical care. They were able to note changes in each other's behaviors. For example, V2 and her veteran friends texted regularly and were able to detect issues through changes in texting patterns, noting the number and type of words used, tone, and speed at which the texts are exchanged. Veteran V3 regularly checked in via text or call with 58 other veterans he had met through PTSD treatment. If he didn't receive a response from one of these veterans, he would check in with other members of the network who may have had information regarding the well-being of the veteran in question. These veteran-veteran mental health support networks are close-knit and provide an outlet for genuine conversation. Veteran V4 noted:

> *"My veteran buddies and I] have experienced some of these traumatic things, and we're able to comfortably get into these hard conversations."* (V4)

It is important to highlight that not all support networks are positive. V3 was the only veteran to report a negative mental health relationship with other veterans. He noted that in his inpatient treatment experience, shortly after Vietnam, he and fellow veterans would congregate to smoke marijuana and drink heavily. He explained that at the time he did not view this as negative, but retrospectively noted that these interactions were not positive for his health. When he stopped drinking and smoking, the relationships with these veterans faded away.

Clinicians further utilize informal veteran-veteran networks in formal treatment during group therapy sessions. They said that veterans shared a cultural bond with one another which promoted exchanges. Clinicians also leveraged intricacies of sub-cultures between branches, generations, genders, ranks, and races. Clinician C7, who treated many African American veterans, explained that care had to be tailored for cultural values and their years of service in the military. Clinicians C6 and C9, explained how important understanding these intricacies was for developing a cohesive, functional group therapy environment. Clinician C6 said that groups spoke more freely when formed according to age and service generation. For example, veterans of the same war typically related well to one another, but if gender was not balanced (e.g., 1 woman to 9 men), the minority group was not likely to participate. Clinician C9 described how group dynamics could be affected if the military rank of the members were not considered:

> *"We have specific dynamics that we're aware of in the group setting. For example, maybe [some veterans] had bad experiences with leadership in the military and we have officers who are participating in the group. So, we try to remain aware of any sort of interpersonal concerns or anything that could affect cohesion or kind of a smooth group process." (C9)*

### *Trusted Others Provide Perspectives to Veteran Behavior*

My findings revealed that veterans relied on trusted others such as friends and family for support in real-world settings. Three veteran participants (V5, V1, and V3) were dependent upon their partners for health care such as taking medication, scheduling appointments, and managing symptoms. Two veterans (V2 and V4) relied less heavily upon trusted others but knew they could lean on their friends and family members if required. One veteran (V3) described having a negative, abusive relationship with a partner in the past. V3 stated that he could not and did not want to rely upon her for support.

Seven of ten clinicians incorporated trusted others into treatment in some form as they had clear access to observing the veteran in real world contexts. C3 and C5 only included trusted others in an educational session on PTSD (when appropriate). C7 conducted therapy sessions in the homes of veterans, and as a result, often interacted with and incorporated family members for education or included their perspectives with the permission of the veteran. C9, C10, C4, and C8 collected information from trusted others. This could be in cases where the veteran suffered from memory loss or was open to including an additional perspective. C4 believed that this was helpful, as veterans may not understand how their behavior affects others. The inclusion of trusted other perspectives as described by C8 provides additional insight and understanding of both veterans and clinicians.

> *"One of the best sources of data is the collateral data that I get from family caregivers and friends that interact with the veteran on a day-to-day basis. That can be really telling and can affirm someone's story. It also provides another perspective which can be very powerful in treatment, helping the veteran gain insight into their behaviors and the impact they're having in their environment."* (C8)

Clinicians explained, however, that trusted others' perspectives were subjective. They may under- or over-report behaviors and attitudes as they directly impact their own lives. Furthermore, clinicians shared that relationships between veterans and trusted others could be delicate. Two clinicians noted that including trusted other perspectives might worsen violence, aggression, or cause damage to an already fragile relationship. Clinician C3, who treats veterans through an intensive program, described the nuances of involving trusted others in treatment:

> *"We bring [a trusted other] in for only a week [for educational purposes]. Ripping off that Band Aid---I don't know what's going to be in there. It could be a little cut, or it could be open heart surgery. Opening up that can of worms in a very short time wouldn't work."* (C3)

Trusted others such as CT1, CT2, and VT4 had limited participation in clinical treatment but were able to see a variety of symptoms in real-world settings. Each had attended therapy sessions with a veteran with PTSD in the past and had provided information regarding real-world behaviors, as they were eager to support them. CT1 described how she could recognize her ex-boyfriend's triggers, such as bags on the side of the road or children crying. She actively watched for triggers and sought to help her ex-boyfriend both in the therapy sessions she attended and in real-world settings. She explained:

> *"I'm no therapist. I've never taken any sort of psychology classes… it's not like that. I just think that [it's important] somebody that cares, that's an advocate almost for you but is also involved and wants to help in connection with other human beings."* (CT1)

As a result of their informal caregiving in the real world, trusted others demonstrated a genuine desire to play a role in the therapeutic journey, as explained by CT1. Another participant, VT4, became involved with her adult daughter's care after she had had a serious mental health episode and the family began to suspect a mental health misdiagnosis. Her daughter requested her assistance in contacting her regular mental health care clinician while she resided in an inpatient facility. Veteran trusted-other VT4 explained how she provided information to the clinician ("her" refers to VT4's daughter):

> *"I knew how important it was to mentally take images and audio recordings [about the incident] ... I don't want to downplay it and I don't want to, you know, amplify it; I want [the clinician] to know exactly what it was. So, I showed [the clinician] how her body was moving... how she was talking. I explained how I went to her house to clean up the blood that was all in the kitchen. And so, I knew that she had taken her hands and fingers and smeared the blood around on the floor because I could see the swirly pattern where she had painted with her [own] blood."* (VT4)

Trusted others, like VT4, were able to give the clinicians information that would otherwise be unavailable. In VT4's case, the daughter had no memory of the entire incident. Not all trusted others interviewed were eager to disclose such information. VT3, explained it would be difficult to decide what was appropriate to share. He did not wish to betray the trust or privacy of his fellow veteran.

### *Non-Human Intermediaries and Veteran-Patient Privacy*

Veterans have access to a variety of non-human intermediaries (i.e., technologies) to support PTSD care, including PE Coach [128], DOD Veteran Link [152], and social networking sites for veteran-veteran communication [143,144], among others. Additionally, various technological advances in the medical field have provided veterans with access to clinically sponsored technologies, such as electronic health records (EHR) and fitness wearables.

Despite such options, clinicians explained that only a small portion of the data assessed about veterans from session to session is collected in an EHR. Only past medical records, standardized assessments, and high-level notes recorded by the clinician are formally logged. They explained that detailed descriptions of conversations, exercises, or reactions to exercises (e.g., subjective units of distress, SUDs) are noted by clinicians in separate, personal files. If trusted other perspectives are collected, these were not formally logged. Clinicians stated they typically spent approximately 10-15 minutes reviewing the patient case in the EHR file prior to the patient appointment. In addition, clinicians said that veterans maintain their own homework and SUDs in paper files or through mobile applications such as PE Coach [128]. Clinicians C3 and C9 both provided intensive outpatient care that included giving each veteran a wearable fitness tracker. They explained that veterans maintained their own quantified-self records from these devices and would verbally share sleep and exercise activity unprompted.

According to clinicians, the disjointed nature of patient data is due in large part to privacy concerns around potential misuse of the data. The patient EHR file is a legal document that can be accessed by the patient and potentially other parties. Clinicians include only what is medically and legally required to protect themselves and the veterans they treat. Clinicians explained that they would not want a veteran or another party to misunderstand or misuse detailed notes they took. C5 said:

> *"The medical record has potential to be used negatively. I tend to think about it in a legalistic way, so I put in things in the medical record that relate to safety concerns and risk. I'm making sure that the plan for the patients' continued course of treatment is in there. Whatever comes up in therapy sessions is not meant to be documented in a medical record. I don't need to write that my patient got in a fight with her husband over doing the dishes."* (C5)

Clinicians noted that concerns of privacy are normal for anyone who is disclosing health-related information. This is especially true for veterans. In the sample, all but one of the veterans expressed some mistrust of the government. For example, V4 explained that he received treatment at the VA but only revealed as much as necessary in order to receive financial benefits. He felt a loss of agency because in exchange for these benefits, V4 signed away his rights to talk about his experiences related to trauma outside of therapy; he cannot write a book or publicize what he saw or experienced. He said:

> *"The government is not entitled to your data. I just don't trust them enough to have it in their hands and have the best interest for the individual."* (V4)

### 3.4.3 Accessing Data to Empower Veterans During Treatment

Individuals with mental health conditions struggle to believe that treatment will improve their condition [28]. This is exacerbated for veterans who, as a result of military culture, tend to be more self-reliant [35,143]. In this section, I discuss veterans' understanding of their own progress during treatment and their expressed need for information access.

### *Noting Progress is Critical for Patient Engagement*

Veteran participants expressed that a feeling of progress while undergoing treatment was critical for continued participation in PTSD therapies. One veteran, V1, lacked an understanding of how treatment had a positive impact on his life. He explained that facing the traumatic memories session after session was too overwhelming to feel like any progress was being made. He eventually quit treatment. V2, on the other hand, felt that treatment progression was clear over the first several sessions, but that progress became more difficult to perceive as sessions continued:

> *"Some weeks [treatment] doesn't feel like it's effective. When I first started, every session had some sort of marked improvement because I was just a wreck. Everything was so hard, simple things like doing the dishes or going to work or just putting on shoes or showering." (V2)*

Clinicians indicated that demonstrating treatment progress was both motivational and informative for veterans. Clinicians devised the means to engage veterans in making sense of the data collected in accessible ways. Once veterans had gone through several treatment sessions, clinicians demonstrated progress by creating visual graphs of SUDs via Microsoft Excel or self-report measures through the EHR system. Clinician C9 encouraged veterans to create line graphs on paper despite having digitized data available, saying, *"We keep their scores in an Excel spreadsheet and can easily print it out. I encourage them to track it themselves on paper for ownership of the process."* This exercise by C9 provided veterans ownership over data and an understanding of treatment progress.

### *Including Data Sources Can Help Verify Patient Progress*

Clinicians suggested that current methods of demonstrating progress could be supported by collecting and displaying additional subjective and objective data. In terms of subjective data, clinicians sought information about behavior outside the clinical office setting, including more timely veteran self-report and outside perspectives from third parties (e.g., trusted others). Three clinicians desired objective, bio-sensing data to demonstrate the body's physiological progress during treatment. C10 said:

> *"I wish we could have something that could provide evidence of improvement through biological measures. We administer symptom checklists, which allows clients to see their positive growth on the chart, but if they were able to see an actual decrease in heart rate or skin response or even cortisol levels, that may reinforce the hard work of trauma treatment." (C10)*

Inclusion of biological measures, as described by C10, served to provide an additional, objective perspective for clinician consideration in treatment decisions and veteran understanding of progress. Though desired, the prospect of additional data to demonstrate progress was daunting for already time-strapped clinicians reviewing multiple data sources. However, both clinicians and patients agreed that demonstrating progress was critical for continued engagement.

## 3.5 Discussion

This research adds to the growing HCI literature on how ecologies of care can inform progress in patient healthcare (e.g., [20,66,76,92,157]) and design of appropriate technology [74]. This perspective can help overcome care-seeking barriers and can highlight opportunities for patient empowerment. It also confirms findings from recent studies that advocate for the integration of trusted others, into the clinical-care workflow, in the wake of trauma [19,87,143,144].

### 3.5.1 Implications for Embracing Military Identity in PTSD Care

Military identities promote attributes such as self-reliance, stoicism, and strength [26,143,171], whereas PTSD therapies demand connection, expression, and vulnerability. These findings have demonstrated that military identity shapes the veteran care experience. Often, the military identity is seen as a barrier to care, preventing veterans from engaging in treatment. Clinicians must break down this barrier by attempting to understand the experiences of military veterans. This lends itself to more successful matching between clinicians and patients, which results in more effective treatment.

Military identities cannot be separated from the veteran. Future technologies can leverage military identity to empower veterans. For example, technologies may serve individual veterans with personalized progress measures by visualizing qualities consistent with military identities, such as acts that demonstrate strength. This can aid in empowering patients by demonstrating progress in their preferred terms while expanding the military-related lexicon of the clinician during treatment. This is akin to adopting an assets-based approach [99] when designing technology for holistic care.

In addition, the results demonstrate that when clinicians showed consideration for military identities and experiences, they were more likely to develop rapport with the veterans in their care. When this did not occur, veterans were more likely to disengage with treatment. Future designs may be able to guide and educate clinicians in cross-cultural competency with military identity. Interfaces may provide conversational prompts which serve to establish understanding between civilians and veterans.

Furthermore, future designs may also consider taking a personalized approach by incorporating predictive profiles for clinician-patient matching. Such technologies may offer concise overviews of successful outcomes across clinician and patient archetypes. Veterans would be able to articulate their military identity. In parallel, clinicians could be provided with insights about veteran's expectations to guide interactions. This would also allow technology to highlight patterns of successes and areas for improvement across treatments and provide support systems to strengthen the dyadic clinician-patient relationship.

### 3.5.2 Implications for Leveraging Multiple Perspectives in Ecologies of Care

A variety of human and non-human intermediaries provide partial perspectives to veteran care ecologies. The study results describe contributions of three human intermediaries to the care ecology including veterans themselves via self-report, fellow military veterans, and trusted others.

Veterans regularly contribute self-report data in clinical sessions. However, this group is disproportionately affected by issues of memory lapses due to the high chance of co-morbid conditions such as traumatic brain injury or alcoholism. Already, clinicians suggest that veterans implement strategies to improve their recall by utilizing apps such as PE Coach or recording their thoughts or dreams on paper or mobile notebooks. Future designs may consider the collection or more timely and accurate self-report data by utilizing smartphones. First, ecological momentary assessments (EMAs) might be utilized to collect data regarding the veteran's mood and activities throughout the day to obtain information on behaviors outside the clinical context to be shared with clinicians. Furthermore, smartphone sensor data and wearables may be able to provide additional information on physical well-being and sleep, as well as application usage. For example, when veterans are instructed to use PE Coach to complete therapeutic homework assignments, passive data sensing (e.g., application usage, location) may be able to provide clinicians with a sense of patient engagement and focus on the task at hand. Such data can also be visualized and presented to patients too [138].

Clinicians shared that they capitalize on veterans' shared culture in group therapy sessions. They carefully formed groups to enhance the dynamics between subcultures, allowing veterans to connect over the basis of shared experiences. While there are toxic relationships inherent to the in- and out-group mentality, military identity seeks to unify groups through habitual exposure. Studies show that veterans find support in online communities [144]. My findings reveal that veterans are able to identify aberrant behavior via in-person and virtual contexts (e.g., texting). In a similar vein, technology could be designed to support military identities in a group setting, leveraging the existing camaraderie among groups of veterans, as peer support has been shown to address gaps in care for mental health [115]. Other platforms include mobile applications (e.g., VA DoD Veteran Link [152]) that can prioritize peer coaches to support veterans in navigating the PTSD treatment journey. Such technologies can create connections between veterans in similar stages of treatment, facilitate positive interactions through culturally appropriate guided conversations, and assist in creating online or virtual events. However, the privacy and confidentiality of veteran-patients' needs to be foregrounded in the design of such online communities.

Trusted others can identify real-world data about veteran behaviors and, in some cases, to provide this collateral information to clinicians. Several clinicians in the study already include the trusted other's perspectives into the PTSD treatment process. These findings emphasize allowing veterans to pick the trusted others to be included as part of their care. They also reinforce the importance of adequate screening along with a flexible inclusion of multiple trusted others. Text messages completed by trusted otherse can also be used to collect relevant information at regular, timely intervals in the real world. A second opportunity for future technology is to educate trusted others on what symptoms, behaviors, and attitudes are useful to report and in what manner. This is important because this knowledge is something that is otherwise gained through the personal experience of individuals suffering from PTSD.

These findings indicate a variety of human and non-human perspectives contribute to the care ecology of veterans with PTSD. For example, clinicians selectively utilize EHR data, their own notes, collateral information from trusted others, and biometric data from wearables (e.g., heart rate, stress level) to supplement patient self-report. Should these data sources be incorporated into future technology, designers must attend to common barriers identified in using patient-generated data within a clinical setting [172]. Technology can coalesce patient data, including individuals' session-to-session progress, cohort progression, and analysis of EHR data through machine learning and data visualization to improve clinician reviews. This would facilitate reconciling disparate data sources to effectively synthesize patient health data for decision-making. Attempts have been made to take into consideration clinicians' need to streamline workflow. However, there need to be new systems that allow access to the data by both patients and clinicians [138]. The inclusion of such perspectives might provide more informed participation in treatment. For example, it can be easily visualized to track progress. Technology must consider how to weigh and display data from each of these subjective, partial perspectives [58] of human and non-human intermediaries in the care ecology. It must consider how to maintain or enhance veteran engagement and empowerment at the center of the care ecology.

### 3.5.3 Implications for Veteran Empowerment

Understanding patient empowerment, a key characteristic in how I define patient engagement in this dissertation, is steadily growing. Early on in my work, I focused on only this characteristic, but later adopted a more comprehensive definition of patient engagement. However, patient empowerment in stigmatized contexts is less understood. Technologies may be employed to help individuals seek out and manage care. They can also stigmatize or exacerbate vulnerabilities in these populations [94,163,164]. In the study, veterans feared Government misuse of their mental health data to negatively affect benefits. Clinicians noted this was possible and subsequently, limited data input.

For veterans to feel empowered, they must have access to monitor and utilize their own mental health data. They should be provided with a transparent understanding of how the data might be used and opt in or out of logging certain information in clear, common language. Research has already explored how such variables can prompt reflection through patient-facing interfaces [95,96,154]. However, further research is needed to explore customization of technology to integrate relevant patient-centered presentation of data for PTSD care.

Another barrier to data collection during treatment is the veteran-patients' mistrust of institutional authorities contributing to feelings of mistrust and surveillance reported in similar health research [176]. I provide two design implications. First, future designs might be created by non-institutional authorities. At this juncture, much research and technology development for veterans is conducted by the DoD and VA. Second, I suggest that disparate data points collection use ephemeral media to display particularly sensitive information. Patients can define such measures to demonstrate and deconstruct treatment progress through measures that cannot be permanently linked to a veteran's records. For example, this type of ephemeral mechanism has been made popular by social media platform, SnapChat [183]. This could be reformatted for medical purposes to utilize data and engage patients.

### 3.5.4 Leveraging Bronfenbrenner as a Framework for Understanding and Design

In Bronfenbrenner’s ecological systems theory (EST) [18], human development is a complex system of relationships affected by various layers of the individual’s environment. When we consider the care ecologies (i.e., ecological system) of veterans with PTSD, we can leverage EST to think about the possibilities for data collection and how a future system may be situated among these many layers. This approach has been used successfully in to determine ecological factors in other chronic conditions[7,95]. Furthermore, it can be used as a basic tool to think through how such a system might affect patient engagement and clinical decision-making. For example, how might environmental influences (e.g., military culture) affect patient perception and use of features of a shared interface?

Below, I present how the findings from Study 1 are conceptualized with Bronfenbrenner’s EST in mind. In reviewing each circle of the EST for the care ecology of a veteran, the following stakeholders and data sources are identified in each ring: self (e.g., self-report, biometrics, cell phone data), immediate (e.g., friends, family members feedback), community (e.g., clinician feedback), societal (e.g., government, regulations), and environmental (e.g., social and culture values such as military culture).

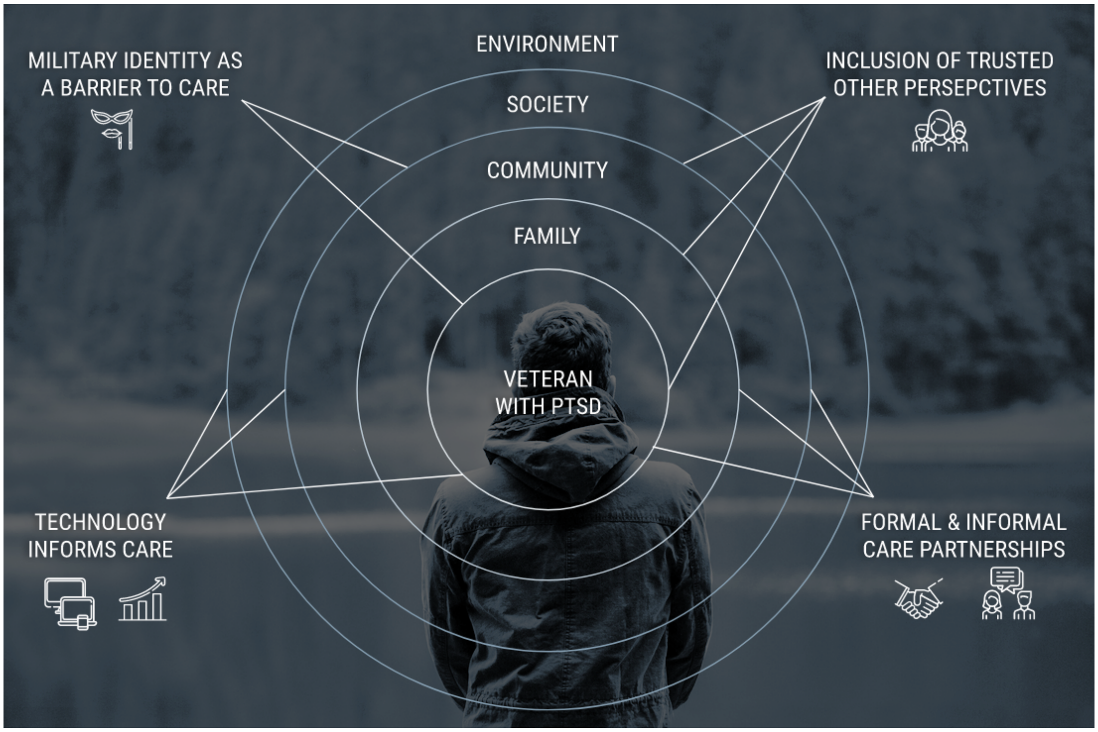


*Figure 4: Care Ecology of a Veteran with PTSD with respect to Bronfenbrenner's EST*

The following chapters are motivated and built upon this conceptualization. In the next chapter, I present an early prototype of what a clinician dashboard could look like in incorporating some of the human and non-human intermediaries identified in this chapter in evidence-based therapy. In Chapter 6, I provide an in-depth investigation of how human intermediaries' feedback at the level of family and community can be leveraged in a shared interface for evidence-based therapies such as PE therapy. In Chapter 5, I expand my understanding of what it means to utilize technology to inform care by introducing a new concept of measuring a therapeutic exercise with sensor-captured patient generated data. I take a closer look at how biometrics at the level of the patient and passively sensed data (e.g., location, ambient noise, and temporal data) collected at the level of the environment might be leveraged.

### 3.6 Conclusion

At the time of this publication, HCI was increasingly investigating complex ecologies of care and the importance of patient empowerment. This work focuses on barriers to therapeutic care among veterans with PTSD and exploring what role technology might play in enhancing empowerment. Drawing on qualitative research inquiry, I uncovered the challenges and opportunities in care-seeking for veterans with PTSD. I discussed how the veterans' military identity might lead us to enriched design opportunities. Future design would likely benefit from leveraging the presence of partial caring perspectives owing to additional human and non-human intermediaries, with the understanding that the veteran must be at the center of the design activity.

Since the time of this study, my understanding of how care ecologies can be leveraged for design has broadened from patient empowerment to considering the cyclical nature of patient engagement and clinical decision-making. The following studies will take a much broader perspective as I discuss the design of future shared interfaces. Furthermore, while this study discusses trauma-based care more broadly, the following two chapters will narrow the scope to exposure therapy while Chapter 6 encompasses evidence-based care for veterans with PTSD.

# Chapter 4: Steps Toward Designing a Clinician-Facing Dashboard for PTSD

## 4.1 Introduction

In this study, I address a clear gap in the literature regarding tools to improve clinical decision-making and delivery of PE therapy which is known to be one of the most effective and highly used therapies for PTSD. Currently, most of the technology built to deliver PE therapy is geared towards improving the PE experience for patients [11,13,128,129,134]. There is a lack of clinician-focused technology. However, clinicians have pressing needs that have gone unmet, particularly those who may be novice in delivering this evidence-based treatment. In this work, I investigated a practical solution to aid clinicians in the form of a clinician dashboard which was originally envisioned to work in combination with PE Coach, an existing application for patients which will be described in additional detail in this chapter.

The goal of this research was to validate whether a clinician-dashboard could improve clinical decision-making by providing additional information regarding patient progress. It explores opportunities for the development of technology to support clinicians in the delivery of PE therapy. I address this gap by first examining the challenges that clinicians face when delivering PE therapy and by designing and evaluating two clinician-facing design solutions to improve clinicians' abilities to document and monitor patient progress and more effectively target treatment. I investigated the following research questions by leading a team of master's students in the human-computer interaction program at Georgia Tech:

- **RQ1:** What is the current IOP process for preparing to see patients?
- **RQ2:** What are current limitations to patient-clinician interaction during therapy?
- **RQ3:** Is the inclusion of trusted others a valuable goal?

## 4.2 Background

In this study, I focus on the treatment of PTSD using Prolonged Exposure (PE) therapy, a manualized therapeutic approach which has been shown to have one of the greatest therapeutic efficacies [10,61]. PE therapy has its theoretical underpinnings in Emotional Processing Theory (EPT) of PTSD; a theory that emphasizes processing the traumatic memory in the reduction of

PTSD symptoms [41]. According to EPT, emotional processing involves activating the pathological network of trauma-related responses (e.g. fear, sadness, unrealistic beliefs about the world) and then weakening these responses [41]. The two main determinants of successful PE Therapy are repeated *in vivo* (real world) exposure to situations that the patient is avoiding due to trauma-related anxiety, and repeated, prolonged imaginal exposure where the patient revisits the trauma memory by visualizing and recounting the traumatic event aloud. The fundamental takeaway of the in vivo and imaginal exposure components is for the patient to learn that the traumatic memory and the trauma itself are two distinct entities. Through repeated in vivo and imaginal exposure exercises, they weaken their responses to trauma-related stimuli. Successful PE therapy results in patients being able to reclaim control over their lives by reducing excessive fear and anxiety [41].

PE therapy can be administered via traditional weekly 90-minute sessions or daily in intensive outpatient programs. During sessions, clinicians discuss the patient's progress, review previous homework assignments, conduct imaginal exposure sessions, guide the patient through emotional and cognitive processing, and assign new homework. The therapist must keep track of the patient's self-report measures via instruments such as the PTSD Checklist (PCL-5) and Subjective Units of Discomfort scale (SUDs). The PCL-5 is used to assess a patient's PTSD symptoms [123] while the SUDs scale measures how distressed the patient is feeling in the current moment. This scale ranges from 0, a state of no distress, to 100, a state of the most distressed the patient has ever experienced [41].

### 4.3 Related Work

Prior work on the treatment of PTSD using PE includes a variety of interfaces. Numerous mobile applications have been developed treat symptoms of PTSD [130]. One of the most popular mobile applications, PE Coach, was developed with the goal of facilitating PE therapy for the patient [84,127]. Functionality of this application includes the ability to record imaginal exposure sessions, enter SUDs, and schedule appointment reminders. Kuhn *et. al.* found that clinicians generally have favorable perceptions of PE Coach [84], however, PE Coach does not currently have a clinician interface. Recent work in the computing field has explored the user requirements for the design of future technology which incorporates the perspectives of various stakeholders including both clinicians and patients [37].

Virtual reality (VR) based applications have also been used to improve PE therapy by enabling scenarios that are realistic yet safe for the patient [4,6,50]. VR has been used to simulate combat environments for veterans [135]. Furthermore, there is hope that the use of VR could increase the utilization of PE therapy [12]. As in the case of mobile applications, VR applications for PTSD have been primarily developed as a tool for patients [6].

Currently technology for PE therapy is geared toward the patient, however, there is also ample opportunity to support clinician workflow and clinical decision-making. For example, these professionals have specific challenges based on their level of experience administering PE therapy [178]. Novice clinicians may be overwhelmed by the manualized nature of PE therapy; they may focus on the implementation of in vivo and imaginal therapy and forego key clinical skills such as listening. Successful PE therapy depends on patients fully engaging with their traumatic memories, and novice clinicians often fear that patients may over engage (e.g., become too aroused). Thus, even though PE therapy has high efficacy, its delivery can be improved.

## 4.4 Methods

To investigate the above research questions, we developed a three-part research design. First, we uncovered requirements for a clinician-facing PE therapy interface via semi-structured interviews and subsequent analysis of the interview data. Based on the results of the interview data, we developed two interface prototype designs. Finally, we engaged clinicians in prototype demonstration sessions to elicit feedback on the designs.

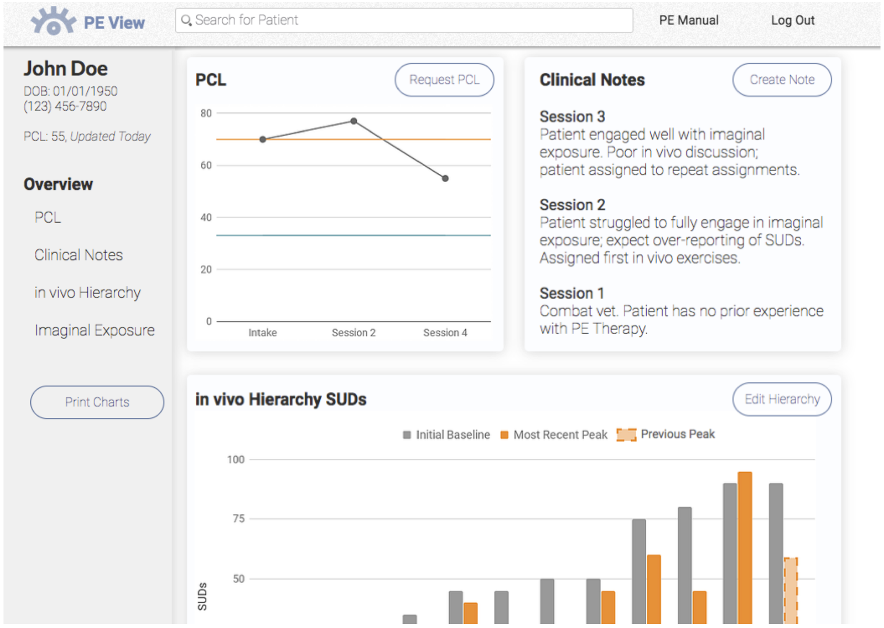
### 4.4.1 Interviews and Thematic Analysis

In the first part of the study, 12 clinicians (10 females, 2 males, age range 30 to 58 years) that practice PE therapy participated in semi-structured interviews that lasted, on average, about 45-minutes. The goals were: (1) to understand the challenges clinicians face when delivering PE therapy, (2) to better comprehend how clinicians assess patient progress and (3) to determine what data clinicians are missing from their existing processes. Audio from the interviews were both recorded and transcribed. Two of the researchers on the team used thematic analysis [23] to analyze the interviews. The entire team of researchers met to analyze, iterate, and develop 28 themes from 120 transcript excerpts. From these discussions, three main themes emerged. These themes include (1) the need for an improved workflow during therapeutic sessions, (2) utility and limitations in patient self-report, and (3) the desire for a better way to assess their patients' symptoms and behaviors outside of therapy. These will be discussed in detail in the results section.

### 4.4.2 Design Alternatives: Creation of Two Interface Prototypes

Based on themes uncovered in the clinician interviews, the team developed two design alternatives. The first was a clinician-facing information dashboard aimed at automating the collection and visualization of patient self-report and homework data. The second was a “Social Sensing System” that would enable clinicians to gather collateral information from people who regularly interact with the patient (e.g., partner, family member, friend) known as “trusted others.”

The information dashboard prototype, or Prototype 1, focuses on the digitization of the PE manual's paper forms to allow for automated visualization of self-report data throughout the therapy. Variables were selected for the dashboard based on interviews with clinicians, the PE therapy manual, and research into the predictive power of various self-report measures [41]. The dashboard design consists of three screens. The first provides a patient overview which graphically displays the patient’s PCL-5 score, in vivo hierarchy progress, in-session imaginal exposure SUDS, and the clinician's notes (*See Figure 5*). The second screen provides a session agenda, homework review graphics, and homework assignment capabilities (*See Figure 6*). The third screen provides an overview of the imaginal exposure sessions. It allows for real-time graphing of SUDS and physiological measures, such as heart rate, one-click capture of patient engagement signs, such as crying or clenching fists, and clinician note entry (*See Figure 7*).



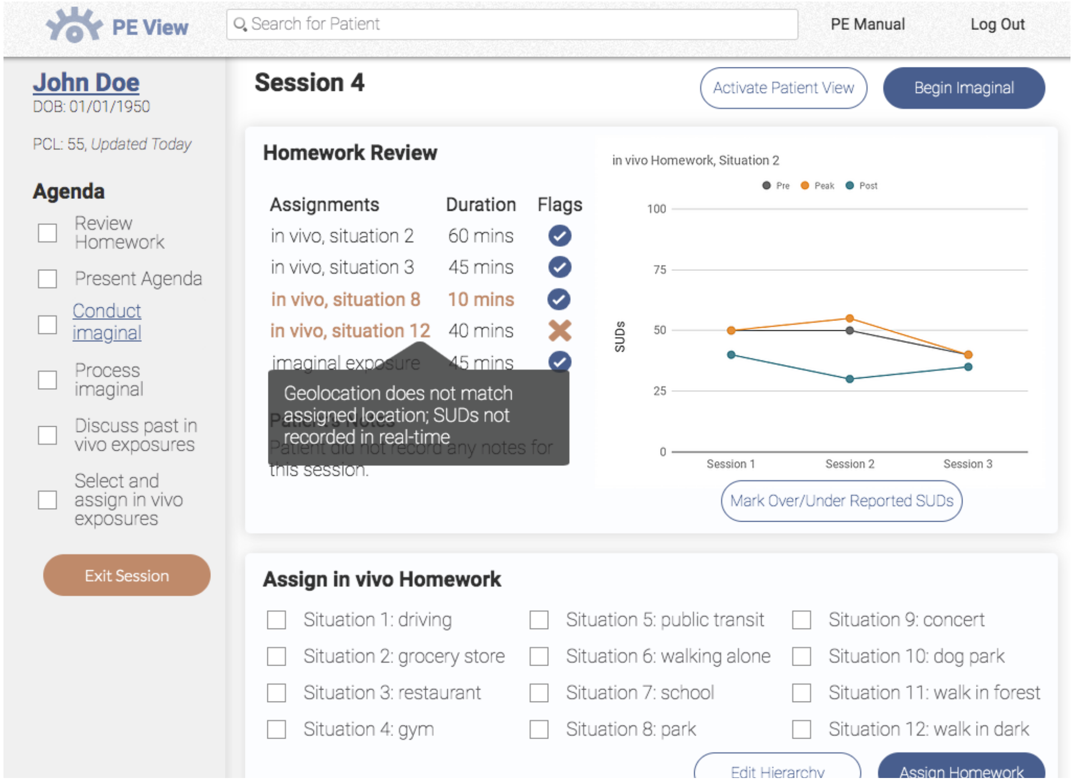
**John Doe**
DOB: 01/01/1950
(123) 456-7890
PCL: 55, *Updated Today*

**Session 3**
Patient engaged well with imaginal exposure. Poor in vivo discussion; patient assigned to repeat assignments.

**Session 2**
Patient struggled to fully engage in imaginal exposure; expect over-reporting of SUDs. Assigned first in vivo exercises.

**Session 1**
Combat vet. Patient has no prior experience with PE Therapy.

*Figure 5: Overview of Clinician Dashboard*



**John Doe**
DOB: 01/01/1950
PCL: 55, *Updated Today*

☐ Review Homework
☐ Present Agenda
☐ Conduct imaginal
☐ Process imaginal
☐ Discuss past in vivo exposures
☐ Select and assign in vivo exposures

| Assignments | Duration | Flags |
|---|---|---|
| in vivo, situation 2 | 60 mins | ✓ |
| in vivo, situation 3 | 45 mins | ✓ |
| in vivo, situation 8 | 10 mins | ✓ |
| in vivo, situation 12 | 40 mins | ✗ |
| imaginal exposure | 45 mins | ✓ |

Geolocation does not match assigned location; SUDs not recorded in real-time

Patient did not record any notes for this session.

☐ Situation 1: driving
☐ Situation 2: grocery store
☐ Situation 3: restaurant
☐ Situation 4: gym
☐ Situation 5: public transit
☐ Situation 6: walking alone
☐ Situation 7: school
☐ Situation 8: park
☐ Situation 9: concert
☐ Situation 10: dog park
☐ Situation 11: walk in forest
☐ Situation 12: walk in dark

*Figure 6: In-Session Interface*

The Social Sensing System prototype, or Prototype 2, has three main sections: (1) a social sensing overview section that enables a clinician to view a trusted other's assessment of a patient's progress (*See Figure 8*), (2) an in vivo section that displays a trusted other's assessment of a patient's in vivo session (*See Figure 9*), and (3) a messaging section that enables a clinician to message a trusted other with pre-formulated questions pertaining to a patient's state and progress (*See Figure 10*).

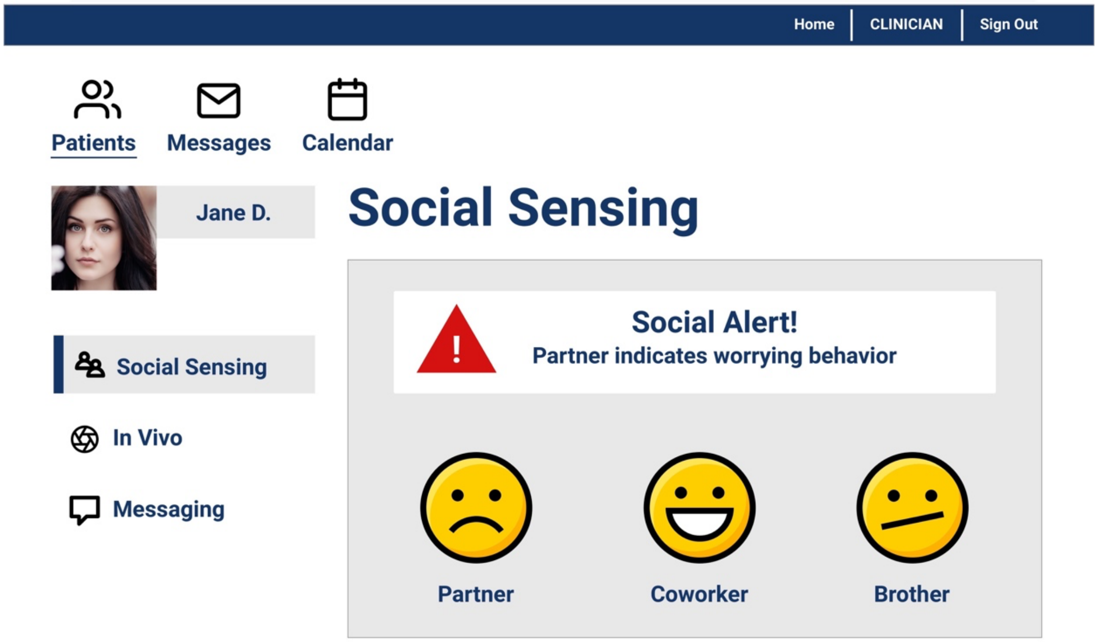
**John Doe**
DOD: 01/01/1950

Imaginal Exposure in Progress
**32 mins, collect SUD in 3 mins**

**Probes**
- What are you feeling?
- What are you thinking?
- What do you smell?
- What does it look like?
- What is your body feeling?
- Where do you feel that in your body?

**Supportive Comments**
- You are doing fine, stay with the image.
- Great job, stay with your feelings.
- Remember, memories are not

*Figure 7: Imaginal Sessions Overview*



Social Alert!
Partner indicates worrying behavior

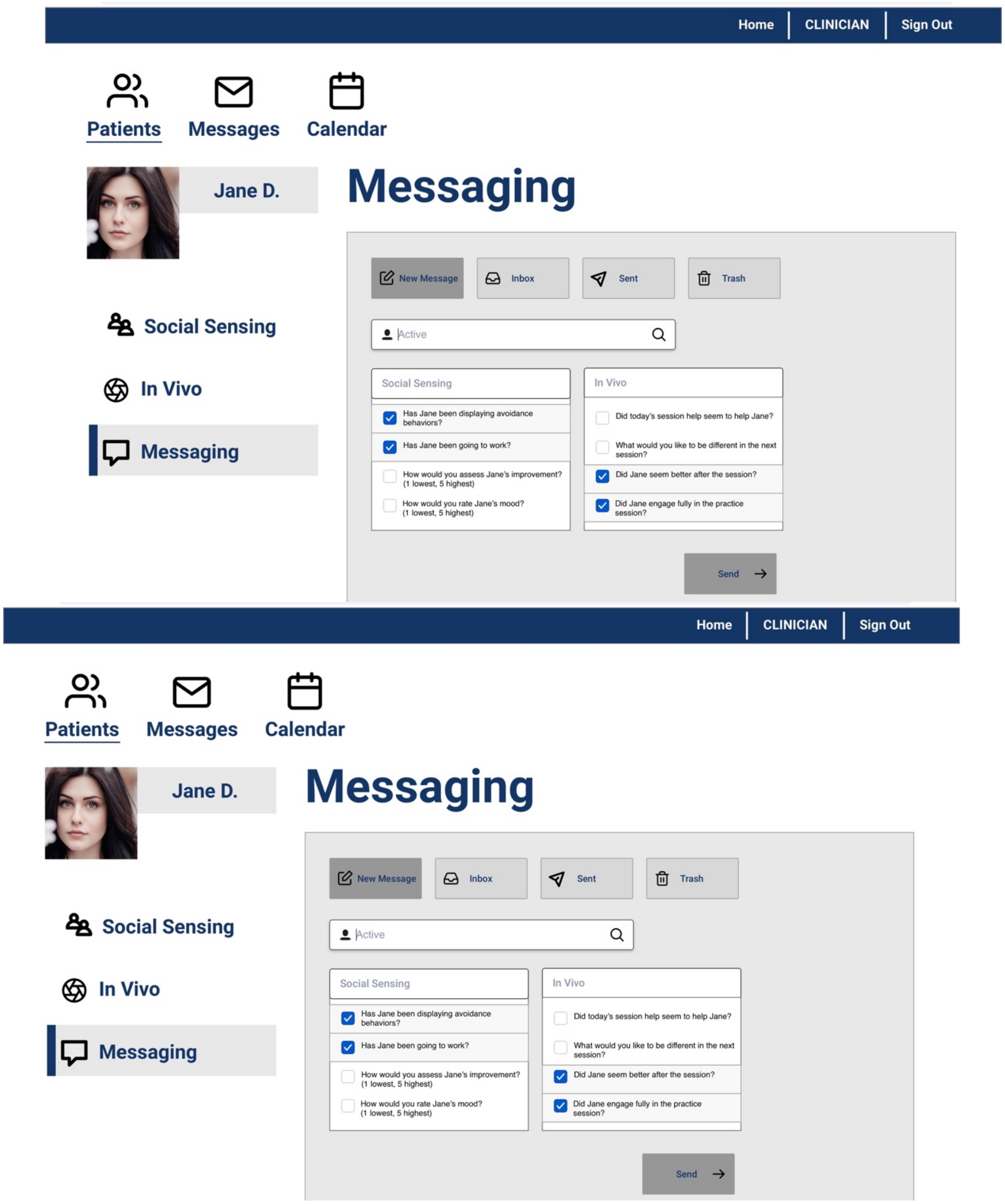
*Figure 8: Social Sensing Overview*

Monday, Mar 1st, 12:00 PM IN-VIVO Session SUDS

PRE: 50 PEAK: 65 POST: 30

Today's session felt like an improvement. I think Jane did really well.

*Figure 9: Trusted Other Assessment of In Vivo Session*



Social Sensing

☑ Has Jane been displaying avoidance behaviors?
☑ Has Jane been going to work?
☐ How would you assess Jane's improvement? (1 lowest, 5 highest)
☐ How would you rate Jane's mood? (1 lowest, 5 highest)

In Vivo

☐ Did today's session help seem to help Jane?
☐ What would you like to be different in the next session?
☑ Did Jane seem better after the session?
☑ Did Jane engage fully in the practice session?

Social Sensing

☑ Has Jane been displaying avoidance behaviors?
☑ Has Jane been going to work?
☐ How would you assess Jane's improvement? (1 lowest, 5 highest)
☐ How would you rate Jane's mood? (1 lowest, 5 highest)

In Vivo

☐ Did today's session help seem to help Jane?
☐ What would you like to be different in the next session?
☑ Did Jane seem better after the session?
☑ Did Jane engage fully in the practice session?

*Figure 10: Clinician Messaging Interface*

*Prototype Demonstration Sessions*

We conducted feedback sessions with five clinicians (4 females and 1 male with age ranging from 31 to 39 years). They had been practicing PE therapy for an average of 4.4 years (±2.4 years).

In order to evaluate the information dashboard, clinicians were first asked to complete a background survey about their experience with PE therapy and rate their current satisfaction with the process of delivering PE therapy on a seven-point Likert scale. Clinicians then completed the following four think-aloud tasks on the information dashboard: (1) prepare for an upcoming appointment with patient John Doe, (2) review John Doe's homework, (3) conduct an imaginal exposure session with John Doe and (4) assign John Doe his next set of homework. After each task, clinicians were asked to rate their satisfaction with the process using the dashboard and were asked follow-up questions about their experience using the system. After completing all tasks, clinicians were asked to provide three words to describe the system and were interviewed about their overall impressions of the interface. The goal of the information dashboard feedback session was to understand whether a clinician-facing dashboard centered on visualizing self-report data would be useful to clinicians.

Feedback sessions for the social sensing interface had six components (1) a device usage survey, (2) think-aloud tasks for each of the three sub-components: the general social sensing feature, the in vivo feature, and the messaging feature, (3) a task interview for each of the three sub-components, (4) a post-task interview, and finally, (5) a System Usability Scale (SUS) questionnaire for the social sensing interface.

The purpose of the device usage survey was to gain insight into the clinicians' technology usage habits. These habits were uniform, as they all used laptops/PCs for their clinical work, though some expressed a desire to use a tablet when interacting with a patient. Think-aloud tasks were performed to both assess whether the clinicians could complete specific tasks using the interface and to gather feedback on features as they were using them. Task-specific questions allowed for further explication of the system features. The post-task interview and the SUS were performed to obtain the clinician's assessment of the system.

## 4.5 Findings

In this section, I describe first the requirements and design implications which were uncovered during the interviews with clinicians. Next, I describe clinician feedback regarding the two prototypes that were developed for this study.

### 4.5.1 Requirements for a Clinician-Facing PE Therapy Interface

Analysis of interview transcripts revealed three main themes which informed later prototype designs. These themes included (1) the need for an improved workflow during therapeutic sessions, (2) utility and limitations in patient self-report, and (3) the desire for a better way to assess their patients' symptoms and behaviors outside of therapy.

#### *The Need for an Improved Workflow During PE Therapy Sessions*

The current process for collecting and reviewing patient data is inefficient and relies on patient self-report and clinician intuition. Clinicians who deliver PE therapy must balance time spent collecting and analyzing data with engaging in therapeutic tasks. Clinicians compromise by verbally engaging patients to share self-reported data while in session. Clinician 5 and 7 explained:

> *"[Any data] needs to be easily accessible, not time intensive, and immediate because if those are not readily available, or I gotta figure it out, then I'm not going to do it." (C7)*
>
> *"One thing that is a challenge for me as a clinician is that there are so many things to be aware of and assess in a short amount of time[...] you want to focus on the therapeutic tasks." (C5)*

While clinicians desire additional data, they do not have time to collect and perform lengthy analysis themselves. They desire a system that allows them to quickly digest relevant information. This presents an opportunity to utilize technology to reduce clinician time spent on such analysis which can support clinical decision-making in-session without over burdening already time-strapped clinicians.

#### *Utility and Limitations in Patient Self-Report*

Patient self-report is crucial for monitoring patient progress through treatment; however, clinicians struggle to effectively monitor the volume of self-report data from session-to-session. This is due, in part, to the large amount of data (e.g., SUDs collected from homework, standardized self-report assessments, etc.) that needs to be processed and analyzed by clinicians before therapy sessions. Clinicians explained that they are able to confidently assess the validity of self-report but struggled to manage volume. Clinician 4 explained:

> *"I put a lot of faith in [self-reports]. I definitely use them to drive treatment, to know when to terminate, when to change.'...[but] your desk starts to explode with paperwork and of course the writing the notes and inputting their scores each week and trying to mention their SUDS." (C4)*

Self-report is critical for clinician assessment of patient progress in PE therapy and their subsequent decisions regarding how to tailor treatment accordingly. However, tracking and making sense of the volume of self-report data presents a challenge. This indicates an opportunity for technology to collect self-report mechanisms and display them in an easily digestible way for clinicians. Already, past research has emphasized the utility of visualizing time-oriented patient variables [2,86]. Research on therapeutic processes within PE suggest several indicators, including decreases in SUDs between exposures and completion of homework tasks [10], that are predictive of treatment outcome.

### *Assessing Patients' Symptoms and Behaviors Outside of Therapy*

During the interviews, clinicians explained that patient behavior varies from the clinical office setting to the real-world. In real-world environments, patients interact with others, perform daily activities, and encounter challenges which impact their PTSD. Accordingly, they expressed a desire to better assess their patients' symptoms and behaviors outside of therapy, including more frequent assessments of symptoms and information about the patient's daily life, even outside the context of self-report. Clinicians said:

> *"More frequent assessment of symptoms or anything like that in their home environments [would be useful]." (C8)*

> *"[I would like to see more] Information about what they're actually doing in their real life. So, if there's a way to observe them and see if they're doing... engaging in safety behaviors[...] just a little bit more information not based on their self-report." (C2)*

This desire for additional real-world data points to an opportunity to utilize technology to collect timely information provided by those who regularly interact with patients in real-world environments. Already, several studies have indicated that trusted others are able to accurately report on patient behavior [19,43].

### 4.5.2 Clinician Feedback on Two Clinician-Facing PE Therapy Interfaces

Two prototypes were presented for clinician feedback: (1) a dashboard aimed at automating the collection and visualization of patient self-report and homework data and (2) a "Social Sensing System" that displayed collateral information from trusted others. The results from these feedback sessions are presented below.

#### *Information Dashboard to Visualize Patient Self-Report*

Overall, the information dashboard received positive feedback with clinicians describing it as comprehensive (n=2), intuitive (n=2) and helpful (n=2). Clinicians thought the system would improve accountability, both for the patient and the clinician, saying:

> *"This seems more organized and easier to notice any discrepancies." (C4)*
>
> *"I like that it's more holistic, and it could be more accurate." (C2)*

Clinicians described the system as a tool their patients could use directly or collaboratively with the clinician. One clinician stressed the importance of allowing the patient to remain in control of the treatment:

> *"Usually now, you bring your form, and you tell me how those things went, and it's in the patient's ballpark in terms of how they want to talk about it[...] they take ownership of their work." (C5)*

However, clinicians were skeptical of two features: (1) clinician notes and (2) the ability to mark suspected SUDs as over- or under-reported by the patient. Since all clinicians in this study already took notes in a separate system, they did not see the need to record or transfer notes to another system. Clinicians thought that the ability to mark SUDs as over- or under-reported made their judgment seem too official. Instead, one clinician proposed a companion metric, such as a perceived unit of distress, that would allow the clinician to rate their perception of the patient's distress without placing official judgment on the reported SUDs.

The in vivo hierarchy and homework review sections of the dashboard had the most usability issues, and several design changes were identified to improve these features. Clinicians were most excited about the imaginal exposure feature, with many saying that it would increase the likelihood of them visualizing the session and that it would save them time by allowing them to graph SUDs and engagement signs in real-time.

The results of the Likert questions from the survey were positive with all dimensions showing improvement using the dashboard compared to the current process (*See Figure 11*). The biggest improvement was in the process of tracking a patient's mental health status, which was one of the main goals of the system.

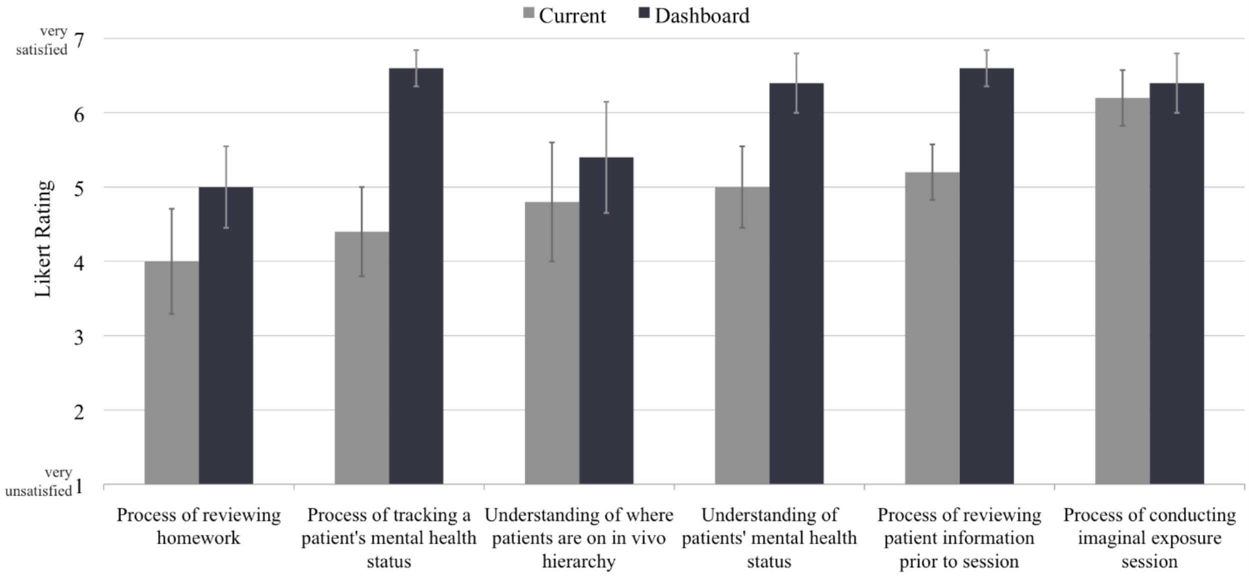


***Figure 11: Likert Results Demonstrate Improved Process with Dashboard Versus Current PE Therapy Process***

*Social Sensing*

As part of the feedback process, clinicians were asked to rank the three social sensing sections in order of importance, all five agreed unanimously on the order: (1) the in vivo section (most important), (2) the general Social Sensing section, and (3) the messaging section (least important). This consistency in ranking indicates the specific use cases for which clinicians want collateral data. Overall, clinicians had positive feedback regarding the fact the social sensing system as whole could provide them with important, missing data. Clinicians said:

> *"I had an outpatient before; it would've been useful to have feedback from his wife about how he was. She was a huge part of his treatment." (C1)*
>
> *"I always want to hear more about what other people think is going on. I get a skewed picture talking to one person." (C5)*

The results of the System Usability Scale were positive as well, with an average score of 89.5 which corresponds to an "excellent" usability rating [162]. However, clinicians voiced concerns that the Social Sensing System might lead to privacy and confidentiality issues that would need to be discussed with the patient prior to inclusion of the trusted other. Clinicians also noted that the Social Sensing section could better emphasize the problematic behavior noticed and better visualize emotions. Regarding the in vivo section, clinicians mentioned that it did not clearly indicate that the SUDs assessment was that of the trusted other and not that of the patient but found this section the most important in assessing the patient. However, they appreciated that the messaging section had a pre-populated question form that allowed them to quickly send desired queries.

### 3.5 Conclusion

To the team's knowledge, no clinician-facing dashboards had been developed for PE or other PTSD psychotherapies at the time of this study. This research begins to bridge a gap in the literature surrounding technology developed for clinicians delivering PE therapy by designing an interface prototype to improve clinical decision-making. Both early-stage prototypes presented in this study were well-received by clinicians, validating the concept and future related research. However, given the scope of the work, the validation was broad, and several questions arose from the findings particularly when thinking about this study in conjunction with Study 1.

First, clinicians in this study mentioned the potential for utilizing this data in conjunction with a patient to afford that patient agency. I began to question how the designs presented in this study might change when designed for patients. How and when could clinicians and patients use this data? How might it inform clinical decision-making and patient engagement? What designs or features would encourage patients to engage in collaborative discussion with clinicians and how would this function in session?

Next, in contrast with the findings in Study 1, clinicians did not indicate that self-report was problematic for reasons of bias. Instead, they were concerned with volume. This contrast in responses led me to conclude that additional investigation into how clinicians assess self-report for homework and SUDs was needed in future research.

Clinicians also indicated a desire to see more data collected outside of the clinical setting to inform their practice in a streamlined way. I began to think about how we might collect these perspectives using human (i.e., trusted others) and non-human (i.e., passive sensing data) and how they could be used during the clinical setting. Not only might these inform patient progress over time but might also serve to provide context to self-report data which was effectively streamlined by presenting real-time graphs in the clinician dashboard in this study. However, as clinicians pointed out, this type of data collection could raise issues of privacy with veterans.

Finally, due to the study only containing clinician perspectives regarding the Social Sensing System, it became clear that I still needed to understand what conditions, if any, this type of system would be acceptable to trusted others and veterans with PTSD.

# Chapter 5: Using Sensor-Captured Patient-Generated Data to Support Clinicians and Patient Self-Report

## 5.1 Introduction

In this chapter, I explore how non-human intermediaries can contribute toward a more holistic picture of the veteran journey through PE therapy. I describe the notion of the Patient Engagement Quotient (PEQ), a unique measure and interface which displays similarity ratings calculated using sensor-captured patient-generated data (sPGD; i.e., heart rate, phone usage, ambient noise, and physical activity) for therapeutic exercises performed under the guidance of a clinician and outside of the clinical setting. I examine how sPGD can be leveraged to measure and investigate what contributes to patient performance in a therapeutic exercise. I also share in-depth information regarding clinician interpretation and planned use of data displayed by PEQ in clinical sessions with patients. I frame the results in the context of situated objectivity and propose the notion of "perceived reference weight," which describes the significance attributed to contextualized data. This is essential in considering how we might support clinical decision-making for individuals with a range of clinical experience.

Recent work has explored the utility of sensor-captured patient generated data (sPGD) in the context of identifying and treating a variety of mental health conditions [4,47,78,101,124,165–167]. Studies have leveraged mobile phones or wearables to collect sPGD such as phone usage, sleep data, and physical activity throughout a patient's day-to-day activities. From this data, studies have been able to predict relapse [165,166] monitor behavioral patterns [165], and investigate how such data might begin to be incorporated into the clinical setting [112,113].

This study extends the research by investigating how sPGD might be utilized by clinicians who are treating veterans with PTSD in intensive outpatient treatment using PE therapy. Using the PEQ prototype as a probe I address the following research questions:

- How can we design an interface using sPGD to inform clinicians about patient engagement during therapeutic exercises?
- How will clinicians perceive the PEQ's utility and usability?
- How can PEQ be used to support clinical workflow and patient engagement?

My research makes the following contributions. My research provides one of the few shared interfaces which displays sPGD to clinicians and patients in the context of mental health [138] for PTSD. I examine how sPGD easily collected through commodity smartphones and fitness trackers can be leveraged to measure and investigate which features (e.g., heart rate, physical activity, ambient noise, and phone usage) contribute to patient performance directly in a therapeutic exercise. I also share in-depth information regarding clinician interpretation and planned use of data displayed by PEQ in clinical sessions with patients.

## 5.2 Related Work

Smartphone applications or wearable activity tracking devices have been used to collect a range of sensor-captured patient generated data (sPGD) in the context of mental health, such as physical activity, sleep data, and phone usage. By leveraging different forms and combinations of sPGD, researchers have examined correlations between sensed behavior in non-clinical activities and the current or future state of mental health for a variety of conditions including schizophrenia [166], bipolar disorder [4,47,100,101,165], depression [78,124,167], and PTSD [112,113].

Mobile phone sensing systems have been used to accurately predict psychotic relapse in patients with schizophrenia [166,168]. Wang *et. al.* [166] proposed a mobile sensing system that collected data regarding physical activity, location, environmental setting, digital communication, and phone usage. Using machine learning models to predict risk of psychotic relapse for patients in an intensive schizophrenia clinic, the study demonstrated significant predictive power from passively sensed metrics as compared to traditional clinical assessments.

Sensing systems for bipolar disorder such as MONARCA [4,47] and MoodRhythm [100,165] aim to support patient self-care and mental illness management while providing relevant information to clinicians. To do this, MONARCA, a smart-phone based healthcare mobile application, collects accelerometer data, location, call-logs, application usage, social activity, physical activity, mobility, voice features, and phone usage. It combines this passive SPG data with self-report assessments of mood, sleep, medication adherence, activity, warning signs, cognitive problem, stress, and alcohol consumption [4,47]. Similarly, MoodRhythm uses the patient's smartphone to collect sound, light, accelerometer, location, social media pattern, and phone use in combination with self-reports of mood [100,165].

Finally, Ng *et. al.* explored the use of sPGD for PTSD by exploring clinician [112] and patient perspectives [113] on incorporating wearable activity tracker data (e.g., sleep quality, calories burned) into an intensive trauma-based care setting for veterans with PTSD. They found that sPGD in this case could enhance patient self-monitoring and noted that it might be possible to identify a relationship between PTSD symptom measures and FitBit [112].

My study builds upon prior research which has investigated the utility of sPGD for mental health conditions, particularly recent work by Ng. *et. al.* [112,113] as I also examine the use of sPGD in an intensive treatment setting for veterans with PTSD. However, in contrast with previous studies, I incorporate sPGD from both a mobile phone and FitBit and it utilize it to directly measure patient performance in imaginal exposure exercise. To my knowledge, this is the first attempt to leverage sPGD to measure patient performance for a trauma-based mental health exercise to support clinical decision-making.

In measurement-based care, clinicians utilize systematic tracking of symptoms and responses to treatment to guide clinical decision-making [90]. In the case of trauma-based treatments such as PE therapy, patients regularly provide self-report measures through the PCL-5, PHQ-9, and SUDs to capture metrics regarding patient response to therapy [41,88,93]. Yet, the validity of self-report is limited as it is inherently biased [46,67]. As past research has noted, sPGD demonstrates promise in contributing additional data from another perspective to measurement-based care [112]. There are a variety of potential benefits in incorporating sPGD into measurement-based treatment for mental health. sPGD provides the foundation for scalable behavioral pattern recognition for clinicians and patients [111]. It can make health data more accessible [78,112,113] and identify trends in treatment [106]. Subsequently, sPGD can be utilized to inform clinical decision-making from a perspective of situated objectivity [112,118] and empower patients to take an active role in their own care [23]. Furthermore, patient-generated data has been found useful in establishing trust between patients and providers and assisting patient-doctor communication at the point of care [105,142] to build stronger patient-doctor relationships [23].

Yet, there are also a variety of perceived challenges in utilizing sPGD in the point of care setting. First and foremost, interpretation [111] and utility [112,113] of data by key stakeholders is a concern. The volume and types of data may not seem directly relevant for clinical purposes and may conflict with existing workflows [6]. Patients may misinterpret data or have unrealistic expectations which can lead to fixation, discouragement [112], emotional triggering [111], or lead them to conclude they are not progressing adequately [23,78]. For example, Ng *et. al.* found that some veterans using Fitbit data in PTSD treatment felt the purpose of collecting the data was unclear and did not trust that the data was meaningful [113]. Second, the addition of supplementary health data can be time-consuming [112,145] and create new barriers in the doctor-patient relationship [145]. Finally, research has highlighted issues of interoperability with other key systems in the ecosystem (e.g., EHR) and concerns for data privacy [37,111]. Patients tend to withhold information that they perceive as personal or sensitive [142], and this may be exacerbated in the context of mental health, particularly for insular groups such as veterans with PTSD who have heightened privacy concerns [37].

To date, studies have examined perceptions of the use of sPGD for measurement-based care. However, none have yet introduced a prototype to elicit specific reactions of stakeholders on the ground in the context of mental health. My study addresses this gap by conducting investigation of how clinicians interpret and plan to utilize sPGD presented by the PEQ prototype in session with veteran patients with PTSD in a point of care setting.

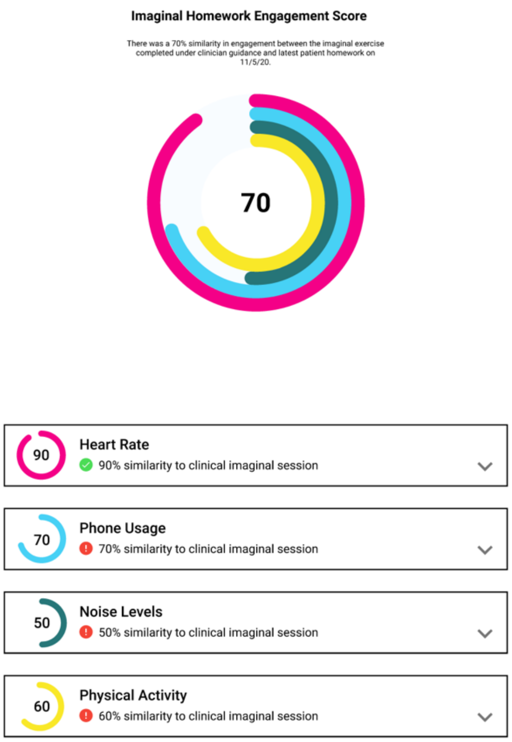
### 5.3 Design of the Patient Engagement Quotient

The Patient Engagement Quotient, or PEQ, is a novel measure that compares and contrasts patient sensor data during clinician led imaginal exposure exercises and for homework sessions throughout exposure therapy (*See Figures 12 and 13*). This is potentially useful to help clinicians and patients understand how patients are performing in exercises at home where they 1) face distractions they would not typically encounter in the clinical setting and 2) do not have clinician guidance to work through the exercise. The sensor data during the clinical therapy sets the baseline for “patient engagement” since the clinician is actively working with the patient to stay focused during this time. The design of PEQ currently focuses on imaginal exposure activities. The purpose of the imaginal exposure is to activate and modify trauma-related fear structures in order to break the cycle of fear activation and avoidance. Through imaginal exposure, patients revisit the memories of the traumatic event by recounting them aloud in vivid detail with the clinician and then, between sessions, listening to recordings of the most recent session’s recounting.

During the clinical session, a patient uses a mobile application and FitBit, to record their imaginal exposure exercise under clinician guidance. When the app is turned on, various data streams including heart rate, physical activity, phone usage, and noise level in the environment are collected to establish a baseline level of engagement for optimal learning. Later, when the patient is ready to do their imaginal homework exercise, they turn on the app and it collects the same data streams that were collected during the in-person clinical session. It then compares and contrasts the patient sensor data detected during the homework session to the sensor measures recorded earlier in the clinical session. These measures will be displayed as a Patient Engagement Quotient on both a clinician dashboard and patient-facing mobile application. Both clinicians and patients can view patient engagement performance from the clinical and homework sessions throughout PE therapy. Measures include:

- A comprehensive PEQ score to give a high-level similarity rating that compares engagement during the clinical session to engagement during homework. This is an average of the scores of all data streams collected.
- Scores and visualizations for each data stream collected.
- Averages from all sessions within each data stream.

PEQ collects and displays comparative data regarding patient engagement in imaginal exposure exercises throughout exposure therapy. Clinicians can use this data to inform their delivery of PE therapy and guide the patient to optimal performance. The patient gets feedback on their performance that allows them to optimize the next homework exercise. They then get additional information that confirms what they did well and where they can improve. In short, the goal of PEQ is to help clinicians to give individualized feedback to each patient and help patients know how well they did during their homework.



Imaginal Homework Engagement Score

There was a 70% similarity in engagement between the imaginal exercise completed under clinician guidance and latest patient homework on 11/5/20.

Heart Rate

✓ 90% similarity to clinical imaginal session

Phone Usage

! 70% similarity to clinical imaginal session

Noise Levels

! 50% similarity to clinical imaginal session

Physical Activity

! 60% similarity to clinical imaginal session

*Figure 12: PEQ Clinician Dashboard*

### 5.4 Methods

The PEQ concept was tested with 10 clinicians. All clinicians were employed by the same mental healthcare facility and elected to participate after receiving an internal email sent on our behalf. Participants were compensated with a $20 Amazon gift card for their time. Table 3 provides a summary of participant information including participant ID, history of relevant clinical practice, technological capabilities assessment, and System Usability Scale (SUS) score [38].

Sessions were conducted primarily by me over video call; a co-author assisted with some of the sessions. Each session lasted between 40 - 60 minutes. First, clinicians shared their experience collecting and evaluating patient self-report for imaginal exposure exercises throughout exposure therapy. Then, they were shown a short video explaining the PEQ concept. Afterwards, they participated in a think aloud session [72] with the interactive PEQ prototype in which they reviewed the PEQ sensor-captured patient-generated data for an imaginary patient. This prototype did not contain real patient data and mock data was used to create tables and visualizations to ascertain if it was realistic. They were asked to share initial impressions of the prototype as well as to determine what PEQ told them about the imaginal exposure exercise, which area(s) of the homework (if any) required clinician attention and how, and the time frame of the available data. After concluding the think aloud tasks, clinicians were then asked about their experience interacting with the prototype in a semi-structured interview. Clinicians were asked to explain the PEQ concept in their own words, how (if at all) they saw themselves using PEQ as a part of their exposure therapy practice, what data (if any) they believed patients should have access to and when. Clinicians were also given an opportunity to provide open-ended feedback. Finally, they completed a system usability survey to evaluate their experience with the prototype.

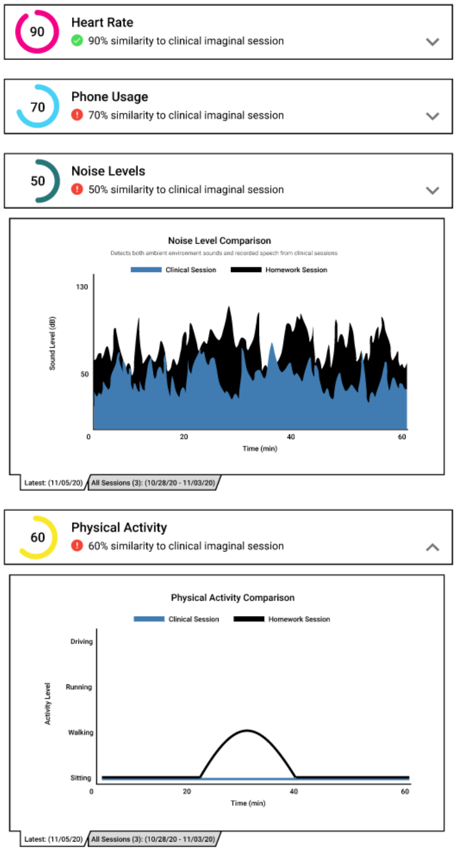
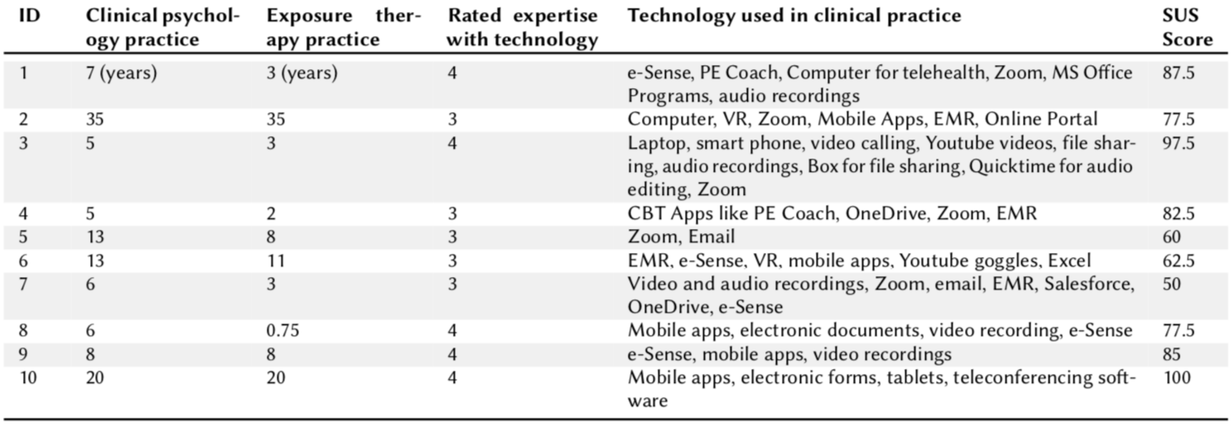


*Figure 13: PEQ Clinician Dashboard with Noise Level and Physical Activity Tabs Open*

All sessions were transcribed by a third-party service and analyzed line-by-line by utilizing thematic analysis [16]. An initial set of 10 inductive codes were generated utilizing key findings from Evans *et. al.* [37] and Ng *et. al.* [112] (e.g., "Clinician and patient relationship," "Self-Report," etc.) and another 10 deductive codes emerged from reviewing the transcripts (e.g., "Clinician Knowledge of Outside World," "Data Access," etc.). In this first round of coding, the 20 codes were applied to the 10 transcripts 447 times and two inductive codes were removed for lack of relevance to the data. A second and third round of coding were performed to further refine and apply the code book. A total of 16 parent codes (e.g., "Self-report") and 24 child codes (e.g., "Self-report quality," "SUDs calibration") were applied 869 times. Clear themes emerged from this data including current clinical practices in evaluating imaginal exposure exercises, interpretation and imagined utilization of PEQ, and possible barriers to use of PEQ**.**

*Table 3: Study 3 Participants*



| ID | Clinical psychology practice | Exposure therapy practice | Rated expertise with technology | Technology used in clinical practice | SUS Score |
|---|---|---|---|---|---|
| 1 | 7 (years) | 3 (years) | 4 | e-Sense, PE Coach, Computer for telehealth, Zoom, MS Office Programs, audio recordings | 87.5 |
| 2 | 35 | 35 | 3 | Computer, VR, Zoom, Mobile Apps, EMR, Online Portal | 77.5 |
| 3 | 5 | 3 | 4 | Laptop, smart phone, video calling, Youtube videos, file sharing, audio recordings, Box for file sharing, Quicktime for audio editing, Zoom | 97.5 |
| 4 | 5 | 2 | 3 | CBT Apps like PE Coach, OneDrive, Zoom, EMR | 82.5 |
| 5 | 13 | 8 | 3 | Zoom, Email | 60 |
| 6 | 13 | 11 | 3 | EMR, e-Sense, VR, mobile apps, Youtube goggles, Excel | 62.5 |
| 7 | 6 | 3 | 3 | Video and audio recordings, Zoom, email, EMR, Salesforce, OneDrive, e-Sense | 50 |
| 8 | 6 | 0.75 | 4 | Mobile apps, electronic documents, video recording, e-Sense | 77.5 |
| 9 | 8 | 8 | 4 | e-Sense, mobile apps, video recordings | 85 |
| 10 | 20 | 20 | 4 | Mobile apps, electronic forms, tablets, teleconferencing software | 100 |

## 5.5 Findings

I organize the findings into three sections. First, to establish a baseline for understanding, I describe current practices in collecting and assessing self-report, clinician workflow, and clinical decision-making for imaginal exposure exercises in PE therapy. Then, I share findings regarding clinician interpretation of the utility and usability of sPGD presented in the PEQ prototype. Finally, I describe how clinicians would utilize this information in the therapeutic setting.

### 5.5.1 The Reality of Conducting Imaginal Exposures in PE Therapy

While conducting imaginal exposures in PE therapy is a specific procedure that includes many small clinical choices that are informed by theory-driven case conceptualization [132], I found that clinician practice extends beyond these guidelines. Accordingly, it is essential that I describe how clinicians guide the imaginal exposure exercise in-session, what expectations they have for at home practice, and how this practice is evaluated in the following clinical session.

### *Guiding Imaginal Exposure Exercise In-Session*

In each session, clinicians guide patients in conducting an imaginal exposure exercise. These generally last between 45-60 minutes (90 minutes for entire session), and the clinician offers guidance throughout to help the patient effectively articulate a narrative of the traumatic event with their eyes closed. They recommend that patients use a smartphone application (e.g., PE Coach) to record the session while their phone is in airplane mode. Clinicians will ask patients to share their SUDs as frequently as every 5 minutes and will always have patients share their pre, peak, and post-exercise SUDs.

In early sessions, clinicians spend time instructing patients on how to calibrate their SUDs ratings. Clinicians help patients set anchor points from 0 to 100 that patients and clinicians will use to assess SUDs scores throughout therapy. Patients express what experiences would produce a 0 (no negative affect), 50 (manageable stress), and 100 (the most distressed you've ever been). C1, C4, C10 explained that this is a highly individualized process and, subsequently, there is a lot of variability in how patients use SUDs. Clinicians must use their intuition to interpret this type of reporting and guide patients on how to best use SUD scoring. C1 explained:

> *"[In speaking with a patient I'd say], I noticed that you said you were about a 70 or 80 in the imaginal exercise] but you didn't seem like you were having a lot of physiological response. Can you tell me a little about that? [Or maybe I have someone who under reports] and they tell me they are at a 30 but I'm noticing they are sweating. I normalize that this is something really different than they are used to doing and it's not just about noting SUDs at any given time but allowing themselves to experience those emotions." (C1)*

Clinicians look for emotional engagement with the imaginal exercise rather than avoidance of the memory. This includes the cognitive part (e.g., "this is dangerous"), the behavioral part (e.g., an urge to leave the situations or look away), and the physiological part (e.g., increase HR). They look for physiological reactions to the exercise such as sweating, flushed cheeks, breathing more heavily, speaking more quickly, and changes in body language. Three clinicians also utilized a device called eSense to measure Galvanic skin response (GSR).

Clinicians also seek to identify avoidance or safety behaviors during the imaginal exposure which might appear as any number of reactions as they are highly individualized, but might include actions such as fidgeting, re-enacting, wringing hands, or hiding their face. C8 shared:

> *"We're doing the imaginal exposure and I notice that [the patient] hides their face. If that's the first time I see it, then usually once we are done with the exercise, I name that behavior and we talk about it as a safety behavior. I ask them why they did it. I also would call it out during the exercise and ask them not to hide their face. And then I know it's a safety behavior they might engage in. I would follow up on it later [in session and homework.]" (C8)*

Clinicians rely on their intuition and ability to manipulate the PE therapy protocol to meet the unique patient needs. Specifically, they discussed over-engagement which is characterized by experiencing an acute level of distress that impacts the patient's orientation (person, place, and time) and ability to identify their immediate environment is indeed safe. For example, clinicians may have patients open their eyes during the imaginal to reduce engagement if they are over-aroused, allow patients to act out memories, or even move around, if appropriate. C7 explained that clinicians who are well-versed in PE therapy are able to do this effectively. They said:

> *"Sometimes you bend a little bit, especially a [clinician] who knows the protocol. They might bend the protocol to achieve what's necessary. So, for example, the person is very over-engaged in their session, and during the imaginal, you say, okay, just do this with your eyes open and then we'll get to the appropriate amount of engagement as we go through the course of treatment." (C7)*

Lastly, clinicians explained that the COVID-19 pandemic which shifted their practice to fully virtual sessions, meant that they would have less control of the in-session imaginal exposure and potentially limited visibility into avoidance behaviors which could occur outside of the camera screen. For example, they might not notice hands wringing or a leg shaking. However, C9 shared that despite limitations of telehealth, there is still more control if your therapist is involved and guiding a patient than if they are not present at all.

Clinicians provide guidance in-session for imaginal exposures for optimal practices which are individualized on a patient-by-patient basis for that moment in time in their treatment whether in-person or via telehealth.

### *Expectations for At-Home Practice*

Following each imaginal exposure exercise in-session under clinician guidance, patients are expected to listen to the recording from that day by themselves for homework. In the context of the IOP, the patients may complete this exercise while at the facility during down time or later from their hotel room. However, during the time of this study, veterans enrolled in the IOP were participating virtually due to the COVID-19 pandemic. As such, they were completing their homework in their normal home environment.

First, clinicians expressed that they expected veterans to listen to the imaginal exposure for the full duration of the recording. Clinicians instruct patients to complete this exercise in a private space with the phone in airplane mode. However, clinicians said this was more easily controlled in an IOP setting and took a more pragmatic approach to homework expectations in the pandemic. They noted that some exceptions might need to be made based on the patient's real-world situation. C7 explained that some patients might need to use headphones so that others in the household did not hear the recording. C1, C3, and C4 said that finding a quiet, private space at home might be challenging or impossible. C3 said:

> *"I pick my battles. Ideally, no, [the patient shouldn't walk] but if that's the only time they can get away - they've got a busy house, quarantine, kids, working from home, they don't have a space that's quiet to sit down and do this, I'd be okay with that. It's not ideal, right? I'd tell them, 'Lock yourself in the car' first, but if [walking] gets them to do [the homework] and assuming that it wasn't avoidance...getting them to engage is the priority." (C3)*

Clinicians also instruct patients to note their pre, peak, and post SUDs just as they would in-session. Patients may use a paper worksheet, a fillable PDF which can be sent virtually to the clinician, or PE Coach to note their SUDs. C2 said that compliance on filling out the SUDs measures for homework was about 50/50 and only because they emphasized the importance and actively used them in session. If a patient forgot, C2 allowed the patient to fill them out retroactively at the beginning of the session. In contrast, C6 explained that they did not place much emphasis on completing SUDs measures for homework and rarely saw worksheets like they had in clinic before the pandemic.

Clinicians aim to have patients complete their imaginal exposure at home as similarly as possible to the imaginal exposure completed in-session. However, they have a realistic understanding of what this might look like and flex their expectations accordingly so long as the patient is engaging with the memory.

### *Evaluating Imaginal Exposure Homework*

Clinicians expressed a sense of underlying trust in the clinician-patient relationship. By and large, they believed patient accounts of whether they had completed the homework exercise and to what degree. Generally, clinicians felt homework compliance was high, and as C4 and C5 pointed out, patients are forthcoming if they have not completed it. On occasion, a patient may not be honest about homework compliance, but this becomes obvious quickly. C3 explained that patients are not able to easily lie about engaging in the exercise. C3 said:

> *"[If they haven't done the homework and say they have,] there's a lack of depth. They can't really talk about it, right? It's like when someone's lying about something, it's either very shallow or overly detailed in sort of the wrong way." (C3)*

Clinicians engage patients in in-depth conversations around homework to better understand and tailor the patient experience. Often, clinicians use SUDs to initiate conversation around homework. They probe for additional information and seek descriptive language to explain when, where, and for how long they engage in the imaginal homework exercise. They ask the patient about any avoidance or safety behaviors that may have taken place, particularly those which were identified in previous sessions. C1 noted that other avoidance behaviors may exist, but it can be difficult for a patient to identify these alone as they may be habitual actions. Clinicians also prompt patients to answer questions regarding the effort it took to engage in homework and what has changed since the last time they performed the exercise. These questions help the clinician understand the patient's progress and how to continuously shape optimal practice. C10 explained that engagement in imaginal homework early on may look different than later in the program; they may allow a patient to act out a memory (e.g., holding up an imaginary gun) during the imaginal early on to increase engagement.

> *"In early sessions, sometimes people act out parts of the memory and that can be a sign of engagement, but as a therapist, I would also be talking with them about doing that less over the sessions...staying with the memory and re-experiencing but not re-enacting. It depends where we are in the sessions whether that's a good or bad thing." (C10)*

Strict homework adherence to a particular regimen is not how clinicians interviewed practiced PE therapy for imaginal homework exercises. Instead, the clinicians seek to better understand the experience of the patient by gathering self-report, tailoring the treatment accordingly, and continually evaluating the patient's habituation to and progress in therapy.

### 5.5.2 Interpreting sPGD in the PEQ Interface

Next, I share findings regarding clinician interpretation of the utility and usability of PEQ prototype sPGD data streams and visualizations. I provide general feedback on the prototype's utility and usability followed by an in-depth analysis of each data stream collected including heart rate, phone usage, physical activity, and noise level.

#### *General Utility and Usability*

Overall, clinicians found the PEQ prototype to be useful and usable for informing their PE therapy practice for imaginal homework exercises. After interacting with the prototype, all ten clinicians filled out a survey to provide a perceived usability rating (*see Table 3*). On average, the PEQ prototype received a SUS score of 78 (anything over 68 is considered to be above average), with seven clinicians providing a score of 77.5 to 100. Three clinicians provided a score between 50 - 62.5.

Clinicians unanimously understood the PEQ concept and were able to articulate its purpose and functionality at a high-level in their own words. Before clicking into the individual data streams, they understood that the rings represented a similarity rating and understood that the number in the center of the rings provided an average of all data streams. Clinicians identified two areas that presented a challenge in interpreting the data. First, what was an ideal and/or realistic similarity rating? Second, they were unsure of what the individual data streams might entail but were able to bridge this gap in knowledge once they interacted with the prototype over time.

About half of the clinicians indicated that visualizing patient habituation (e.g., reductions in SUDs from session to session) to therapy over time might be more useful than general averages.

#### *Heart Rate*

Clinicians shared that heart rate provided useful information regarding patient performance in homework. Six of ten clinicians felt they would address heart rate with the patient while one stated they would use it for their own knowledge. They felt collecting comparative heart rate data over the course of all sessions could potentially demonstrate the body's physiological response to PE therapy and demonstrate progress over time. In reading the interface, most clinicians focused on the heart rate activity comparison graph showing heart rate (bpm) against time of the imaginal exposure exercise. C3, C6, and C7 articulated that when reading the graph, they were looking for similarities in heart rate peaks around the same points in time to determine patient performance. C6 shared that heart rate would be a useful indicator for her as a clinician to determine habituation and would inform how she shaped therapy, but that she would not discuss this with a patient from session to session. In contrast, C9 felt this was the only piece of the PEQ prototype that they would continually visit with the patient as it was singularly telling in terms of demonstrating habituation. C4 felt similarly and said that heart rate data could be particularly useful visualization for patients who are struggling to engage in treatment.

> *“Heart rate can be one indicator of how emotionally engaged they are, especially if this is a patient that we’re seeing a lot of avoidance and that they’re having trouble emotionally engaging with the memory after we've done a few repetitions.” (C4)*

Clinicians did question what heart rate might look like in real patients and how this might change their view on the utility of the data stream. C1, C2 and C7 questioned what heart rate might be able to show in terms of patient performance. C1 questioned:

> *“[For homework the heart rate data is] little bit lower, so that looks theoretical but it’s a good theory [of what could happen].” (C2)*

C3 questioned whether the FitBit would provide high enough quality data to conduct heart rate variability analysis, though, they noted this was likely outside of the concern of an average clinician. C8, C10, and C7 acknowledged that heart rate had some utility but would prefer a GSR data stream.

### *Phone Usage*

Clinicians were able to easily interpret the number of calls, number of contacts, and time spent calling, texting, and utilizing apps. In the prototype, I displayed data to demonstrate the patient was engaging in all these behaviors during homework. Perhaps unsurprisingly, nine of ten clinicians stated they would use this data stream as part of their practice. C4 and C9 explained that they imagined this data would be particularly helpful early on in treatment as they could catch and correct it early. C1 believed collecting and visualizing this data could open doors to behaviors not previously detected by the patient. He said:

> *"Sometimes I think a call or a text comes in and they don't think about it; it's just kind of natural to [respond]. And so that would be kind of a learned habit that we can talk more about and work on not engaging [with calls or texts] with when they're doing the homework. I think some of this data is information that maybe they wouldn't talk to you about maybe when you're asking about how their homework went." (C1)*

However, six clinicians were confused about the functionality of the phone usage data stream. All six assumed the phone would be in airplane mode as is standard in their current recommended instructions for imaginal homework exercises in session and for homework (even when using an application like PE Coach). As a result, they imagined that the patient had not complied with that request. C1 and C7 also questioned where the indicators for a paused recording were on the graph given that phone calls had taken place. C7 thought that perhaps it also picked up apps running in the background of the phone rather than those in active use. C3, C7, and C10 questioned whether phone usage included usage of the PEQ mobile application itself. C3 shared a statement that demonstrates this confusion in interpreting the similarity score and data stream details:

> *"Phone usage would be a big one [for my attention] if [it] was high. If similarity, I guess, was low, that would be a big concern for me." (C3)*

While phone usage received a strong reaction from clinicians, interpretation was variable, and clinicians struggled to understand what phone usage during the imaginal really meant.

### *Physical Activity*

Seven of ten clinicians indicated that they found physical activity to be a useful source of information for patient performance. C1, C2, C6, C7, C8, and C10 indicated that this could provide some additional context to homework performance. It might show that a patient was engaging in avoidance behaviors. C1 said:

> *“Walking for a few minutes might mean that they were also engaging in other things like chores or things around the house.” (C1)*

However, C3, C6, and C7 explained that while physical activity was not ideal, it might be the only way that a patient was able to complete the homework. C3 and C6 said that walking might be okay, especially early on in therapy, so long as it was not avoidance behavior. Clinicians stated that walking was preferable to driving as they should be devoting their attention to homework to properly engage. C7 said:

> *“I have had patients say, 'I went on a walk, and I listened to my imaginal.' And I’m like, 'I would prefer that you did not do that.' But I do also feel like sometimes that may be a thing that comes up, especially with COVID and people working from home, [sometimes] there no other place.” (C7)*

After reviewing this data stream, five clinicians asked if it was possible to see smaller movements they typically address (e.g., fidgeting, wringing hands, shaking legs). C4 and C6 initially mistook the physical activity graph to depict data representing these smaller movements. C4 said:

> *“Within sessions [I] will talk with patients about how much they’re fidgeting, if I notice a leg shaking, if I notice they’re covering their face or moving their hands a lot, fixing their hair a lot. So, this is really nice that this tracks it. And even within session, patients don’t always know in session how much they’re moving around. They’re so in the imaginal that unless I point it out to them, they don’t know, so this would be a really nice way to have some objective data saying, 'look, you’re moving around quite a bit. What’s going on?' We really want your activity level to be pretty low. We want you sitting still, hands on your lap. I think that could facilitate a conversation about what’s happening in session, but then also having a peek into what’s going on during their homework session, too.” (C4)*

Clinicians did find some utility in physical activity but noted that movement may be okay for some patients, especially early on. Several clinicians desired the ability to see smaller movements.

### *Noise Level*

Noise level in the environment received mix reviews from clinicians. Six stated that they found the data stream useful but noted it had less utility than other data streams collected. C1, C3, C4, and C10 explained that they would assume the noise levels in the homework environment would almost certainly be higher than in the clinical environment, which are abnormally quiet. C10 said that they expected a higher noise level, particularly in earlier sessions as the patient was acclimating to best practices in PE therapy. C1 and C9 pointed out that noise levels could be especially relevant for telehealth as it might help manage the clinicians' expectations around what was realistic for both the imaginal exercise completed under their guidance and for homework. C9 said:

> *"Noise levels is a cool one because you would expect not to have any noise problems inside a therapist's office. This is interesting to think about in terms of telehealth. So, you know, now that we do so much over telehealth, I guess we'll see a lot less controlled in-session things [like noises in the background]. But I'd still expect more control if your therapist is actually watching you [than for homework]." (C9)*

Seven of ten clinicians had some confusion about the utility and functionality of noise levels. C2, C6, C7, C8, and C9 struggled to understand what noises the sensor stream was detecting; was it the recording or just ambient noise? How did it work if the patient was wearing headphones? What happens if there is a loud noise on the street while the data is being collected? C1 raised a concern of relevance to veterans who have a heightened sense of privacy concerns. He expressed confusion over how the app collected noise, in what format, if it was associated with the patient's name, and how it was stored. C6 and C7 questioned what an optimal noise level really was inside and outside of the clinical setting. C5 and C6 weren't sure how to interpret a similarity rating between the imaginal exposures. C5 said:

> *"I'm thinking about what information I don't have that could be the attribution for the higher level of noise during homework versus in the PE session. But either way, so what? I really don't know what to draw from that." (C5)*

While noise level could offer some insights into patient performance, clinicians stated that they might already expect a difference in noise levels. Furthermore, they had several questions regarding the functionality of noise levels that required clarification.

### 5.5.3 Integrating PEQ sPGD into Imaginal Exposure Exercises

Here I describe how clinicians would address the sPGD data presented by the PEQ prototype in therapy. I also discuss clinician perspectives on patient data access and barriers to use.

*Providing Feedback to Patients*

Clinicians indicated that they would utilize the data presented by PEQ in conjunction with their already existing processes for evaluation such as SUDs, PCL-5, verbal report, and clinician intuition. C2 said:

> *"If their SUDs aren't going down, if they don't seem to be making improvement, I'm going to look at this and I'm going to say, I think this is why. I think you're not really engaged in your imaginal exposure, you're doing other things, so that's why it's not getting better. So just use it as another bit of data." (C2)*

Most of the clinicians said they would integrate PEQ data into their already existing flow for evaluating homework exercises. They would ask general questions about how the patient felt the homework went, what changes they might have noticed, and if there were any distractions. By asking these open-ended questions, they would allow the patient to respond with or without the data or go through the data together and discuss the best way to move forward. C10 shared:

> *"I would probably start with a more open-ended question about how they felt like their homework went. And if they didn't bring up that they were distracted and doing other things on their phone while they were supposed to be listening, then I would say, oh, well, in looking through PEQ, it looks like there were some interruptions during your exposure. Let's talk about that. What's going on? Why were you getting calls, and then, getting more specific. And from looking at all that, I wouldn't want to nitpick 20 different things with the patient. I would kind of try to put it under, if it's appropriate to put it under one umbrella of, let's find a quiet place next time where you can be by yourself and not interrupted, you know, turn off the getting calls and getting notifications while you're doing this. And you know, set in giving some more specific instruction in how to make a quiet place where they can focus just on doing their imaginal exposure." (C10)*

However, there was sense among four clinicians that using this data could introduce the risk of a patient feeling criticized. While they felt the data could be useful, discussing it with a patient has to be a balance between providing useful feedback and ensuring engagement. This would have to be determined on a patient-by-patient basis. C9 explained:

> *"I do think that one downside to this could be that we don't want to be like 'hey, you were walking around during your imaginal!' We don't want to wag our finger at patients. But we do want to make sure they're engaged. So, we need to balance those two things." (C9)*

Clinicians indicated that many of the sensor streams would be best addressed early on in treatment, particularly when the patient was more likely to engage in some of these distractions and when they were still in the learning phase. Afterwards, clinicians envisioned that PEQ, or parts of it (e.g., heart rate) could be visited periodically.

### *Data Access*

There was variability in opinions surrounding data access. Clinicians had distinct opinions on what data they would allow patients to see and when. Three clinicians (C1, C2, C3) believed patients should gain access to all their PEQ data immediately after finishing the exercise at home. That way, they could review it and bring it into the session ready to discuss it. Half of the clinicians (C4, C6, C7, C9, and C10) believe that patients should gain access to all their PEQ but only once they were in-session with the clinician. They worried that patients might not understand how to interpret the data or might fixate on it without clinician guidance. C8 believed that patients should have access to all their data but when should be determined by the needs of the patient. They said:

> *"If someone is very prone to worry or rumination that might not be someone that I would give access to right away. I don't think it would be harmful; I just think that it could be something that they look at and then really think about a lot, and it might take away from the main work, which is just doing the imaginal exposure." (C8)*

The only clinician who did not believe patients should have access to all their data was C5. They shared that they would share data only if it was noteworthy. She said:

> *"If I'm reviewing the data and there is nothing in particular that jumps out at me, I'm not sure I would find a clinical reason to share it with the patient. But I might do that if there's something that I want to talk about with the patient." (C5)*

In general, clinicians believed patients should have access to all their PEQ data, but *when* they ought to receive access varied.

*Barriers to Use*

A variety of barriers arose in my conversations with clinicians. First, and perhaps most obvious, is the time integration of this sPGD would take. It is one more demand on top of an already demanding therapeutic process. C7 said:

> *"I don't know is [this] a discussion that takes two minutes? Or is [it] a discussion that's now all of a sudden taking 30 minutes and pulling away [from the rest of the session]?" (C7)*

Furthermore, as insinuated in the data access section, clinicians are not confident that patients will be able to interpret this data on their own. C3 expressed:

> *"Patients might not know what to do with all this information." (C3)*

Concerns of data privacy, particularly for the veteran population, was mentioned by three clinicians. They worried that this technology might feel overly intrusive and that veterans might have concerns over what was collected, how it was stored, and for how long. C1 said:

> *"[The veteran] population is even more sensitive to privacy concerns, so they would probably want to know a little bit more about, you know, what is recorded as far as sound [for example]." (C1)*

There was also concern from one clinician regarding how data collection through the phone and FitBit might be cost prohibitive for some patients. C1 questioned how the volume of data collected might not align with what their smartphone plans allow.

## 5.6 Discussion

Through my investigation of the PEQ prototype, I contribute to the growing body of literature which examines the use of sensor-captured patient-generated data (sPGD) for clinical mental health [5,47,165,166,168]. Previous research has investigated the usefulness of incorporating passive mobile sensing systems [5,47,165,166,168] and wearable devices [113,167] to measure physical activity, phone usage, sleep quality, and more to indirectly assess mental health conditions. In measurement-based care, these practices have been shown to improve patient-doctor communication and establish greater levels of trust [106,142]. Ng *et. al.*'s application of FitBit tracking data to intensive trauma-based care for veterans with PTSD suggests that passive sensing systems can improve patient self-monitoring habits [113].

However, when examining reasons for non-use, veterans shared that they did not see a clear connection between the FitBit tracking and relevance to therapy goals. In the design of PEQ, I extend the research of the application of sPGD in clinical mental health by directly measuring imaginal exposure exercises. Thus, I make explicit the connections between sPGD and therapy practice. In presenting the PEQ concept through an interactive prototype, I also elicit specific reactions from clinicians about how they might use such data on the ground in appointments with patients. This contributes to knowledge around clinical decision-making using such interfaces in a realistic context and builds upon how such data can be leveraged to visualize patient performance [138]; PEQ further expands the reach of this design by making it accessible to patients.

The use of sPGD is one of many efforts to include additional perspectives to create a more holistic understanding of mental health status for veterans with PTSD in clinical therapy [5,37,113]. However, as Ng. *et. al.* point out, while sPGD is free from some of the biases of self-report, it is not fully objective [112]. Instead, they suggest a shift to "situated objectivity" [118] which combines the notion of 1) "mechanical objectivity" in which sensor data creates a frame of reference for interpreting self-tracking information and 2) "trained judgement" in which experts are relied upon for contextualization in knowledge formation. They highlight how clinicians may play a critical role in reframing and refocusing data interpretation for patients [112].

In considering the role of trained judgment in interpreting sPGD data in the context of mental health, it is crucial to consider the level of experience of the clinician involved. My study interviewed PE practitioners whose extensive experience enables them to anticipate the needs of patients and individualize the practice of PE therapy to meet those needs. Individual clinician practices may then be reflected in the sPGD data collected for each patient. While this may be interpretable at an individual level, aggregate forms of sPGD from multiple patients may pose some nuances and require additional investigation to uncover meaningful patterns.

Conversely, novice clinicians may require more support than what is currently present when interpreting PEQ data. As pointed out by an expert clinician, it is possible that patient's at-home practice may outperform the clinician-led session when the clinician is a novice. While this is an edge case, the current design of PEQ assumes that the patient performs their therapeutic activity better under the guidance of a clinician. Considering the skill of the individual interpreting the data leads us to an extension of situated objectivity. Specifically, the latter considers the non-systematic way in which experts contextualize self-tracking data. Thus, "perceived reference weight" describes the significance attributed to contextualized data. For clinicians, when expertise is high and self-report is consistent, the reference weight of self-tracking data is low, acting as a supplemental source to inform decision-making. When expertise is high and self-report is unreliable, the reference weight of self-tracking data is high, leading the data to be a more influential source for discussion.

It is important to note that I did not have the opportunity to test the PEQ prototype with truly novice clinicians, which are the individuals who may be most in need of decision support in delivering PE therapy [210]. It would be interesting to determine how use of sPGD might be utilized by novice therapists directly. How might their interpretations of the data and perceived use differ from the expert clinicians enrolled in this study? In addition, the data in my study was "dummy data" and while designed to look realistic, it did not represent real patient data. Future work should also determine how clinician opinions and usage of the utility of sPGD streams vary from patient-to-patient and if we can learn any meaningful patterns from cohorts of patients. For example, how might sPGD collected in-session vary between patients that have combat trauma versus military sexual trauma? Is it possible to predict when habituation will occur among sub-populations of veterans? And how will patients interpret and react to the use of this data in therapy?

Finally, it is crucial to note that while my original intention was to include patients in this study, it was not possible due to recruitment barriers imposed by the COVID-19 pandemic. Despite my best efforts to recruit patients who were currently or had been enrolled in PE therapy, I was unsuccessful. A prototype and conceptual video have been developed along with all study materials. Future work should investigate this perspective to determine the viability of PEQ in supporting patient engagement.

### 5.7 Design Implications

In this section, I share several design implications useful for future designs that utilize sPGD to measure patient performance in shared interfaces to support clinical decision-making and patient engagement.

### 5.7.1 Facilitate Customization

Clinicians demonstrated distinct preferences for specific data streams, data access, and how they would approach the use of this data in-session with patients. Future interfaces should allow clinicians to customize their own dashboards (e.g., choose preferred data streams) as well as patient access to data. The clinicians were very clear that patient access would be based on individual patient profiles; the implication was that uncurated data streams could have a negative implication on some patients' treatment performance.

### 5.7.2 Highlight Use Cases

Regardless of clinician or patient-level of expertise, clinicians have limited time to incorporate sPGD into their workflow. One approach to streamlining clinician training is to provide use case scenarios that clearly show how technology works, what is measured and how this is reflected in the sPGD. For example, ambient noise level was one data stream that was unintuitive for the clinicians. Thus, I could have presented a scenario whereby ambient noise levels could explain how a similarity rating can be established if the user is wearing headphones or how the system handles a loud street noise. Similarly, heart-rate visualizations could be used to show the clinician circumstances where the patient was habituating to treatment.

### 5.7.3 Identify What Data is Collected and Stored

Activities like imaginal exposures are deeply personal. Clinicians expressed concern over the storage of this data and the need to protect patient privacy. Past studies have also highlighted legal liability from the storage of such data [48]. Future designs should avoid storing personal health information when possible and abstract to sPGD data points only. For example, rather than storing the audio content, sPGD stores only the decibel levels. Furthermore, clear guidelines and policies should be displayed for both clinicians and patients. Patients should also have the opportunity to decline transmission of the data from any homework session recorded to protect their privacy.

### 5.7.4 Existing Technology Impacts Use

Existing technologies affected clinician interpretation of sPGD data. First, due to the functionality of PE Coach, clinicians expected that patients would be able to utilize PEQ on airplane mode. This is not the case but did impact the interpretation of data and the instruction clinicians said they would provide to patients. Second, three clinicians used eSense to measure GSR. As such, clinicians felt heart rate was less precise than the data they were accustomed to using. Future designs could consider these existing workflows and accommodate their incorporation on clinician preference.

## 5.7 Conclusion

Clinician intuition and self-report are fundamental to the delivery of psychotherapies, however, technologies such as the PEQ can be leveraged to support clinical decision-making. Through this study, I present an in-depth investigation of how sPGD can be used to directly measure a therapeutic exercise (i.e., imaginal exposures) and be leveraged to support clinician's understanding of patient performance outside of the clinical setting. I highlight the nuances of clinician practice of guiding imaginal exposure exercises, how sPGD from commodity devices are interpreted and how this data would be used on the ground in therapy sessions by clinicians. Sensor-captured patient generated data utilized in the PEQ can be leveraged to provide a more holistic picture of veteran mental health progress through a patient-centric approach.

# Chapter 6: Perspectives on Integrating Trusted Other Feedback in Therapy for Veterans with PTSD

## 6.1 Introduction

In this chapter, I continue the investigation begun in Chapter 4 regarding the Social Sensing System[163], a concept which leverages trusted other feedback for veterans in therapy for PTSD. This research has demonstrated that accounts of trusted others can provide additional context into real world behavior relevant to clinical decision-making and patient engagement. I will describe a two-phase study with clinicians and then later veterans with PTSD and trusted others and will detail that while trusted other feedback may provide a unique and useful perspective, key design features and considerations of underlying relationships must be considered. I will also investigate the power dynamics through the mechanisms and conditions framework [45] in the Social Sensing System and consider what this means for the design of a shared interface in this context.

Evidence-based therapies (e.g., Prolonged Exposure [31]) can promote PTSD recovery and rely mostly on the patient's self-report. However, recent work has identified the potential for utilizing social support networks [5,19,37,130] as a supplement to patient self-report for veterans undergoing clinical treatment for PTSD. This data is important because it provides unique and/or corroborative information about a patient’s therapy progression. Past research has shown that individuals who regularly interact with patients are usually involved in their care (i.e., trusted others). Trusted others can reliably report on the behavior of those with PTSD [9,54]. Research also suggests that approximately 80% of adults are willing to identify trusted others and to provide them consent to observe and rate their behavior for mental health purposes [3]. However, the collection and use of such trusted other data has not yet been systematically explored in the context of evidence-based therapies for PTSD (e.g., exposure therapy). There are open questions about the interface that would be optimal to engage trusted others, patients, and clinicians to promote clinical outcomes.

In this research I address the gap in knowledge about what interfaces could optimize incorporating trusted others into evidence-based therapies. The goal was to design a Social Sensing System that allows trusted others to communicate with clinicians about patient related behavior associated with PTSD symptoms. In this two-phase, mixed method study I investigate the following research questions:

- What are ideal feedback text experiences as veterans progress through clinical treatment for PTSD from each participant group's perspective?
- How can we design the Social Sensing System with these findings in mind?
- How will participant groups perceive the Social Sensing System will affect patient engagement and clinical decision-making?

### 6.2 Related Work

Existing literature has studied the role of social support in promoting mental health and well-being [169] and an essential component of social support comes from trusted others such as families and friends [164]. For people with mental health challenges, previous work shows that patients with less supportive and stable social networks tend to be more psychologically distressed [52,172]. In the case of PTSD patients, PTSD severity is found to have a significant association with perceptions that support members are not receptive or ineffective [26]. Veterans with PTSD–depression symptoms are at higher risks for suicidal ideation when perceiving low social support [37]. There have been efforts in including trusted others into mental health care as multiple studies have noted success in improving mental health by incorporating interventions to strengthen their social support network [26,44,131,188]. Evidence suggests social support can reduce likelihood of treatment dropout [65]. To date, however, limited work has explored the engagement of trusted others in designing technologies to support PTSD recovery [21].

Despite the benefits of including trusted others in care, there are perceived challenges. First, trusted others can find it hard to offer care appropriately [27]. Second, when trusted others provide support, they are also subject to risks of declined mental well-being and impaired intimacy due to compassion fatigue [11,50]. Relationship dynamics between patients and trusted others are often affected by the trauma, which requires them to work together to cope with emotional distress, rebuild shared beliefs, and define new goals [7].

Feedback and support from trusted others such as families and friends work as a cornerstone for decision support and supportive community in health management, which are critical components of both patient engagement [69] and chronic care [10]. However, how to better incorporate trusted others into psychotherapy is less studied. In the case of PTSD, current practices for assessment and diagnoses include a wide range of clinician-administered interviews and patient self-reports [8,104,109]. To date, researchers have not yet developed standardized and evidence-based assessment methods for PTSD treatment that gather data from trusted others who could provide valuable data given their capability to observe the patient's daily functioning and the relative objectivity of their perspectives.

Currently, the inclusion of trusted others in psychotherapy practice is mostly limited to those who work as caregivers, particularly populations that may have limited insight into their own conditions, such as children. In this situation, ecologically valid informant measures have been developed [147]. In PTSD therapy, while empirically supported informant measures for childhood PTSD have emerged [84], the available informant measures for adult PTSD have weak or unknown psychometric properties [81,200]. Despite the dearth of trusted other assessment tools, clinicians encourage their patients to collaborate with trusted others to better understand and monitor symptoms and to facilitate the patient's engagement in therapy [2]. For example, a trusted other can accompany the patient to a safe but avoided public setting such as a grocery store and note the patient's engagement in unhelpful avoidance behavior (e.g., a patient may ask his trusted other to control the shopping cart and choose grocery items while the patient actively scans for threats) [156]. Data collected from trusted others is typically gathered from unstructured interviews that aim to understand how symptoms manifest within social contexts (e.g., the patient's home) [2].

There is no known research comparing adult PTSD self-report data to other-report data with respect to validity, reliability, and utility. However, systematic differences are anticipated [147], as clinicians often expect trusted others to have different expectations and perspectives than patients and provide clinically valuable data the patient is not comfortable with sharing or able to acknowledge [156]. Therefore, soliciting and incorporating information from trusted others requires clinical sensitivity and full informed consent. My work aims to address this gap of understanding potentials and barriers in including trusted others in PTSD therapy, and at the same time, to provide empirical insights of designing for stakeholders involved in the process.

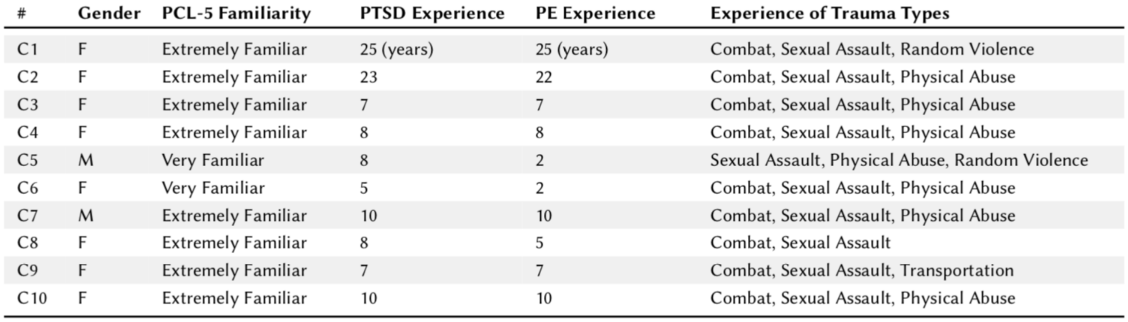
## 6.3 Methods

In this section, I describe the two-phase mixed-method study with clinicians, veterans with PTSD, and trusted others. This study was approved by the Georgia Institute of Technology Institutional Review Board. All participants were compensated with a $20 Amazon gift card for their time.

### 6.3.1 Phase 1: Clinician Perspectives

In the first phase of the study, I investigated clinician perspectives (“C”, N=10; *See Table 4*) on collecting social support feedback. Clinicians were recruited through a partnership with Emory Healthcare Veterans’ Program that provides clinical therapy to veterans with PTSD. All clinicians who participated were experienced in working with combat-related or sexual assault-related traumas.

*Table 4: Study 4 Clinician Participant Details*



| # | Gender | PCL-5 Familiarity | PTSD Experience | PE Experience | Experience of Trauma Types |
|---|---|---|---|---|---|
| C1 | F | Extremely Familiar | 25 (years) | 25 (years) | Combat, Sexual Assault, Random Violence |
| C2 | F | Extremely Familiar | 23 | 22 | Combat, Sexual Assault, Physical Abuse |
| C3 | F | Extremely Familiar | 7 | 7 | Combat, Sexual Assault, Physical Abuse |
| C4 | F | Extremely Familiar | 8 | 8 | Combat, Sexual Assault, Physical Abuse |
| C5 | M | Very Familiar | 8 | 2 | Sexual Assault, Physical Abuse, Random Violence |
| C6 | F | Very Familiar | 5 | 2 | Combat, Sexual Assault, Physical Abuse |
| C7 | M | Extremely Familiar | 10 | 10 | Combat, Sexual Assault, Physical Abuse |
| C8 | F | Extremely Familiar | 8 | 5 | Combat, Sexual Assault |
| C9 | F | Extremely Familiar | 7 | 7 | Combat, Sexual Assault, Transportation |
| C10 | F | Extremely Familiar | 10 | 10 | Combat, Sexual Assault, Physical Abuse |

Sessions lasted between 30 and 45 minutes and were conducted via video call. First, clinicians completed an online survey in which they were asked to consider which questions from the Post-traumatic Stress Disorder Checklist (PCL-5)[17], they believed trusted others could answer and would be useful for clinical decision making. The PCL-5 is a correspondent self-report measure of PTSD based off the Diagnostic and Statistical Manual 5 (DSM-5) symptoms. It is organized and written for non-clinical persons. The clinicians were asked to identify the 10 most important questions, then order PCL-5 questions from most important to least important. Then they were asked to re-word the PCL-5 questions so that trusted others could better understand the items. Afterwards, clinicians participated in a semi-structured interview where they were asked 1) what behaviors trusted others might be able to observe, 2) how the questions could be formatted and the interval for collecting this information from trusted others 3) and how, if received, clinicians might use this data in the therapeutic setting. The data collected in this phase was used to develop feedback text questions for trusted others as well as the protocol and storyboard of the Social Sensing System concept used in Phase 2 of the study.

### 6.3.2 Phase 2: Veteran and Trusted Other Perspectives

The goal of the Social Sensing System is to allow trusted others to provide text-message based feedback about a patient's PTSD related behavior for use in clinician-led therapy. This is not a concept that veterans or trusted others are familiar with. Thus, we utilized findings from the first phase to develop a set of activities that would make the Social Sensing System concept understandable to veterans and potential trusted others. To illustrate and assess the Social Sensing concept, we created a storyboard and demonstrated it to veterans (“V,” N= 10), trusted others (“T,” N=8), and two individuals who participated in both roles (“VT,” N=2; S*ee Table 5*). In it, we depict a realistic scenario of a veteran opting in to using the Social Sensing System on the recommendation of his clinician (*See Figure 14*). He identifies a trusted other to use the application. We developed a scenario that depicts avoidance of “large gatherings,” one of the top-rated behaviors that clinicians indicated trusted others could share. In the scenario, the veteran and a friend make plans to attend the fair together but upon arrival, the veteran chooses not to go in because they do not want to be around crowds. The trusted other receives a text message from the Social Sensing System which asks, “How often does your Veteran avoid certain people, places, conversations, activities, or objects?” They respond with a “4” from Likert scale options of 1 (never) to 5 (always). Afterwards, the veteran reviews the data in-session with clinicians.

*Table 5: Study 4 Veteran and Trusted Other (TO) Participant Details*

| # | Role | Mode | Age | Ethnicity | Gender | Received or know veterans who received PTSD therapy | Completed or knows veterans who completed PTSD therapy |
|---|---|---|---|---|---|---|---|
| V1 | Patient | Video call | 36-40 | White | M | Y | N |
| V2 | Patient | Video call | 36-40 | White | M | Y | N |
| V3 | Patient | Video call | 31-35 | Black or African American | M | Y | Not sure |
| V4 | Patient | Video call | 25-30 | Prefer Not Say | Prefer Not Say | Y | Y |
| V5 | Patient | Video call | 31-35 | White | M | Y | Not sure |
| V6 | Patient | Video call | 46-50 | White | M | Y | Y |
| V7 | Patient | Video call | 31-35 | Prefer Not Say | F | Y | N |
| V8 | Patient | Video call | 36-40 | White | M | Y | N |
| V9 | Patient | Video call | 46-50 | White | M | Y | Y |
| V10 | Patient | Video call | 31-35 | White | M | Y | Y |
| T1 | TO: Spouse | Video call | 25-30 | Hispanic or Latino or Spanish Origin | F | Y | N |
| T2 | TO: Spouse | Video call | 41-45 | White | F | Y | Y |
| T3 | TO: Friend or family member | Video call | 46-50 | Asian | M | Y | Y |
| T4 | TO: Friend or family member | In person | 46-50 | White | M | Y | Y |
| T5 | TO: Spouse | In person | 36-40 | White | F | Y | N |
| T6 | TO: Spouse | Phone call | >50 | White | F | Y | Y |
| T7 | TO: Spouse | Video call | >50 | White | F | Y | Y |
| T8 | TO: Spouse | Video call | >50 | White | F | Y | Not sure |
| VT1 | Patient & TO | Video call | 31-35 | White | M | Y | Y |
| VT2 | Patient & TO: Spouse | Video call | 41-45 | White | F | N | N |

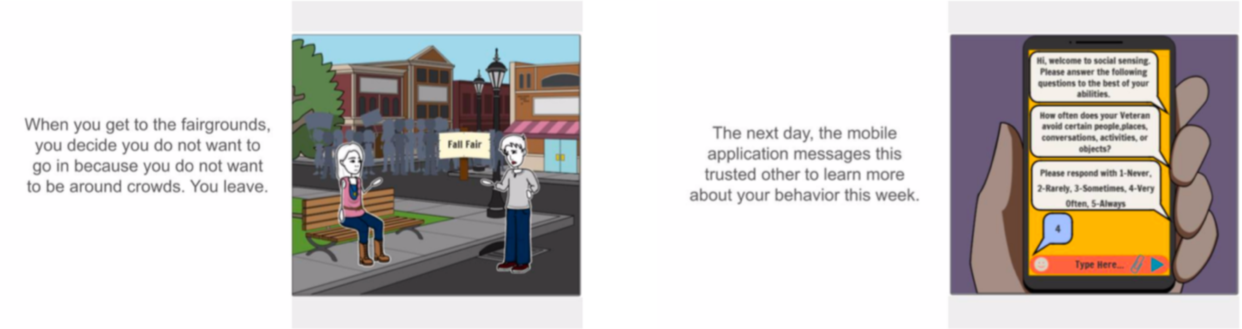


*Figure 14: Select Images from the Social Sensing System storyboard depicting avoidance*

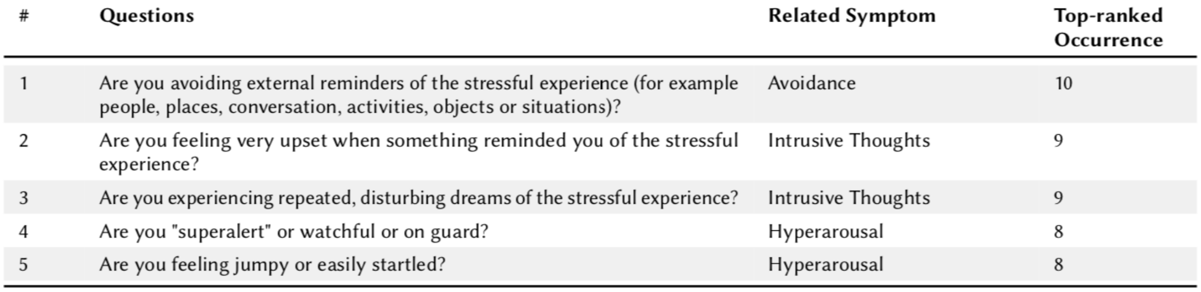
Sessions lasted between 25 - 60 minutes. Nineteen participants were asked basic questions about their military service or their relationship to a service member, viewed the storyboard, and participated in a semi-structured interview to assess their level of interest and ability to use the Social Sensing System. They were asked what kind of feedback they believed a trusted other could provide and their level of comfort with sharing that information. Afterwards, they filled out a survey based on questions developed by clinicians in phase one in which they assessed their level of comfort answering the question (about a service member) and provided a sample answer, if appropriate.

### 6.3.3 Data Analysis

A third-party service transcribed the audio files. Each transcript was coded, line-by-line using thematic analysis. In the first phase of the analyses, a series of inductive codes were generated. I created codes for PTSD symptoms from the DSM-5 such as "Avoidance" and "Hypervigilance." I also developed inductive codes based on trust, choice, and the patient-doctor relationship in mental health [103] resulting in codes such as "Autonomy," "Power Balance," and "Trust." As the transcripts were reviewed and codes applied, deductive codes such as "Misidentification," "Non-observable behavior," and "Nature of the relationship" emerged. The first, second, and third authors met after each round of coding to continually review and refine the codebook. The final codebook from phase one was applied in phase two with the same iterative process. Several new codes emerged from this phase including "Existing Involvement," "Impact on the Relationship," and "Comparing Reports." A final round of coding was performed on transcripts with the full code book by the first and third authors to ensure all themes were documented.

The survey data was analyzed using descriptive statistical analysis. For the clinician survey, the participants were asked to consider which questions from the Posttraumatic Stress Disorder Checklist (PCL-5) of the Diagnostic and Statistical Manual, Fifth Edition (DSM-5), they believed trusted others could answer and would be useful for clinical decision making. The PCL-5 is a DSM correspondent self-report measure of PTSD symptoms, meaning it is already organized and written for non-clinical persons [15]. They were then asked to re-word and order 10 questions from the PCL-5 in order from most important to least important. To understand this data, the team looked at which questions were consistently most highly ranked. This identified the symptoms of most interest and use to clinicians in therapy. The five most highly ranked can be seen in Table 6.

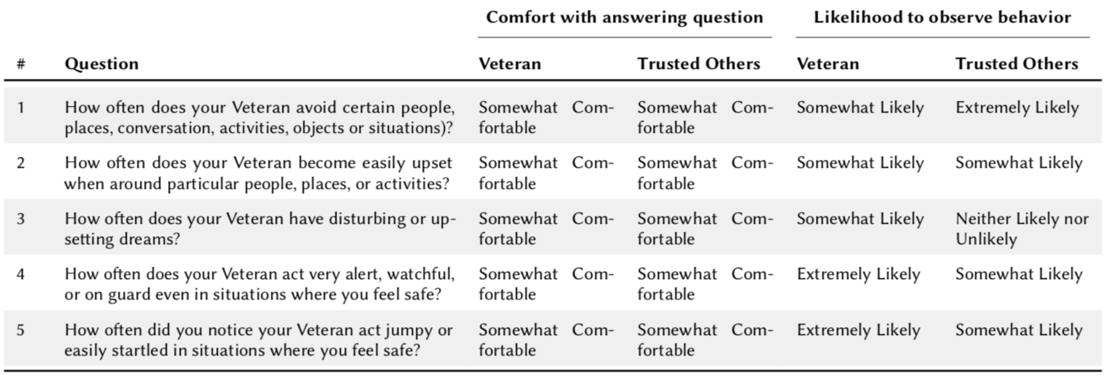
***Table 6: Clinician ranked symptoms of most interest and use in therapy.***
***Occurrence refers to the number of times each question was ranked in the top 10 by clinicians.***



| # | Questions | Related Symptom | Top-ranked Occurrence |
|---|---|---|---|
| 1 | Are you avoiding external reminders of the stressful experience (for example people, places, conversation, activities, objects or situations)? | Avoidance | 10 |
| 2 | Are you feeling very upset when something reminded you of the stressful experience? | Intrusive Thoughts | 9 |
| 3 | Are you experiencing repeated, disturbing dreams of the stressful experience? | Intrusive Thoughts | 9 |
| 4 | Are you "superalert" or watchful or on guard? | Hyperarousal | 8 |
| 5 | Are you feeling jumpy or easily startled? | Hyperarousal | 8 |

To create the veteran and trusted other survey, I utilized findings from the clinician survey as a base. Participants were asked to choose an option on a Likert scale regarding their comfort with each feedback question and the likelihood the behavior identified in the question would be observed. Using the numerical equivalent of each answer on the Likert scale (i.e., somewhat likely = 4), the population mean answer was calculated. This mean identified the average response for each question across participants. These average answers as reported by veterans and trusted others can be seen in Table 7.

*Table 7: Comfort and Likelihood of Questions by Veterans and Trusted Others*



| | | Comfort with answering question | | Likelihood to observe behavior | |
|---|---|---|---|---|---|
| # | Question | Veteran | Trusted Others | Veteran | Trusted Others |
| 1 | How often does your Veteran avoid certain people, places, conversation, activities, objects or situations)? | Somewhat Comfortable | Somewhat Comfortable | Somewhat Likely | Extremely Likely |
| 2 | How often does your Veteran become easily upset when around particular people, places, or activities? | Somewhat Comfortable | Somewhat Comfortable | Somewhat Likely | Somewhat Likely |
| 3 | How often does your Veteran have disturbing or upsetting dreams? | Somewhat Comfortable | Somewhat Comfortable | Somewhat Likely | Neither Likely nor Unlikely |
| 4 | How often does your Veteran act very alert, watchful, or on guard even in situations where you feel safe? | Somewhat Comfortable | Somewhat Comfortable | Extremely Likely | Somewhat Likely |
| 5 | How often did you notice your Veteran act jumpy or easily startled in situations where you feel safe? | Somewhat Comfortable | Somewhat Comfortable | Extremely Likely | Somewhat Likely |

### 6.4 Findings

In this section, I build a specific use case for the Social Sensing System, highlighting when this system functions and fails. I also share themes that emerged from the data regarding the future design of the Social Sensing Concept and its perceived use by the three participant groups. I divide the findings into four sections. First, I describe key characteristics of trusted others and their relationships with veterans. Next, I discuss what behaviors trusted others can observe and if it is appropriate content for a text message question for the Social Sensing System. After I determine content, I discuss the imagined format and cadence of text messages from the system. I conclude with the perceived use of the system by the three participant groups.

### 6.4.1 The Social Sensing System: A Viable Use Case for Trusted Other Feedback

Most participants (28/30) agreed that they would want to use the Social Sensing System as part of the trauma-based therapy process. In this section, I share how each participant group viewed identifying appropriate trusted others within their proximity. Then, I highlight how the Social Sensing System is most appropriate for veterans and trusted others in relationships characterized by high levels of communication, trust, and existing involvement either formally or informally in veteran mental healthcare.

#### *Trusted Other Roles and Proximity*

In this study, I defined trusted others to participants as “trusted individuals who interact with the veteran regularly.” In responding to this definition, clinicians and veterans shared that they believed trusted others could be spouses, adult children, close friends and family members. Trusted others who participated in the study were representative of these responses. In addition, T4 was the uncle of a veteran with PTSD and also acted as religious counsel to other veterans with PTSD. V6 was the only participant who wanted to include his young adult children who were under the age of 18.

Several clinicians, veterans, and trusted others believed that any individual who would act as a trusted other should be in regular physical proximity to the veteran. Five clinicians said that veterans should first think about selecting someone from their household who would be able to see their behaviors. VT2 and V4 explained that the individuals they trusted and were close to lived out of state, and accordingly, could not act as their trusted others. C6 explained how they would encourage a veteran to select trusted others and said:

> *“I would say at first, when they are trying to identify trusted others, to think within their home. And then, if there is someone [outside of the home] who sees them on a regular basis [to include them].” (C6)*

However, some veterans interpreted 'regular interaction' to include not only physical but digital proximity, suggesting that technology can facilitate visibility into behaviors worth reporting in the Social Sensing System. V5 explained that he talks to his friends most when playing video games through a Discord server. V3, V6, and VT2 shared that veterans will connect with trusted others over phone calls and text messages. V3, who speaks to his mother-in-law daily, explained that she could act as a trusted other for him despite living out of state. He said:

> *“She's just really on point. I know text does not fully communicate things like a face-to-face conversation but she's weird like that. [She will say] 'Are you having a rough day?' or 'You must be having a good day.' She just knows and she's always right.” (V3)*

Individuals with physical and digital proximity to veterans on a regular basis were considered to be appropriate for roles as trusted others by participants.

### *Strong Relationships as the Basis for Using the Social Sensing System*

At the crux of the Social Sensing System is the assumption that a veteran is willing and able to identify trusted others to participate in reporting. Seven veterans identified at least 2 individuals and no more than 4 to act as their trusted others. This aligned with clinician expectations that 2-5 individuals could make up a veteran's Social Sensing System team. However, my findings indicate that avoidance and isolation behaviors associated with PSTD can make it difficult to reach this number. VT2 did not feel she had a trusted other to participate. V7, while close to her sister, did not want to be a burden and was actively trying to reduce her reliance on her. C3 explained that lack of social support is a critical challenge for veterans with PTSD. She said:

> *“It would be nice to have at least 2 or 3 [trusted others] so you aren't relying on 1 person. But not everyone is going to have someone and not everyone is going to have more than one.” (C3)*

My findings suggest that informants are already commonly part of veteran mental healthcare, particularly when relationships are strong and have an underlying sense of trust and open communication. T1, T2, T5, and T8 were, or had been, actively involved in their veteran's clinical mental health care by scheduling appointments, speaking with counselors and staff, and managing medications at the veteran's request. T1 had the most regular involvement in providing collateral information to her spouse's clinician on a biweekly basis. She said:

> *"My husband has his session, and then after he's spoken to the counselor, the counselor says, 'Can you have your wife call me sometime next week?' And I make a phone call and we go over how he's been doing in those two weeks...I often get off the phone with the counselor and [tell my husband] what he asked me about. I always thought that open channels of communication are better for helping him cope with [his PTSD]." (T1)*

Six clinicians reinforced that the Social Sensing System would be most appropriate for relationships with a high level of trust and communication. C1 and C4 already incorporated informants' observations of general changes and sleep patterns, respectively. VT1, V3, V5, and V6 explained that the individuals they identified as trusted others knew when they were having issues and had talked about those behaviors with them openly. V5 explained that they had been comfortable enough to ask informants to report his behavior to his clinicians in the past. He said:

> *"At several points I had people near me write statements or letters to my doctor to try to help explain what they had observed and other perspectives. Which a lot of times helps a clinician have a better understanding of you know objective third party of what's going on." (V5)*

Two trusted other participants that were willing to use the Social Sensing System had limited involvement in their veteran's care despite their desire to be included. They felt they saw behaviors worth reporting to the clinician. T10 had often asked her husband to be involved but he refused. She questioned whether he even attended his mental health appointments because he had committed suicide. T5 had pushed her husband to receive therapy and said that she had spoken to her husband's counselor once without his permission after overhearing his telehealth appointment. Now, he tries to have his telehealth counseling appointments when she is not around. She said:

> *"One time he was talking to his clinician on the phone, he said something, and I said, 'No, that's not how it is. You need to tell her exactly how it is...and she asked me what I thought I saw...he tries to do [his counseling] when I'm not around now or he won't tell me when he actually has counseling, so I don't get to just sit there and listen anymore." (T5)*

Even if a trusted other has information to report, the Social Sensing System may not be appropriate in these situations. T2 and T10 expressed concern that if their veterans learned of the feedback that they would stop sharing anything with them at all. The data also suggests that even veterans in strong relationships wondered if the Social Sensing System might negatively affect their relationships. V3, V4, V5, V6, and V7 said depending on what was reported, they might be upset, and it could cause tension with trusted others. V5 said:

> *"I think it could change my relationship with people who might know someone is constantly thinking that I'm being crazy, I might end up…putting some people off or limiting my interactions with them because they do respond negatively, and I don't want the added stress in my life." (V5)*

The data suggests that strong relationships with an established sense of trust, communication, and existing involvement in formal or informal care are most likely to be successful using the Social Sensing System. This design cannot function for veterans who are isolated and may cause additional stress on relationships where trust, communication, or involvement in care is low. Finally, there is a sense that the data that is communicated by the trusted other must be narrow and focused so that it does not add stress to the veteran's life.

### 6.4.2 Imagined Reporting Through the Social Sensing System

When engaging participants, I first asked each participant group what they believed trusted others could report in an open-ended fashion. Afterwards, they were asked to review the specific PCL-5 related tasks. Accordingly, the findings are organized into five categories which include PTSD symptom clusters of trauma re-experiencing; avoidance of trauma-related situations, thoughts, and feelings; negative alterations in thoughts and mood; and hyper-arousal [56] and other observations.

#### *Trauma Re-Experiencing*

The findings suggest that some trusted others are in the position to identify and report on symptoms related to trauma re-experiencing such as upsetting memories, nightmares, flashbacks, or emotional distress [56,152]. Reporting on these symptoms requires physical proximity, verbal report of these symptoms from the veteran, or knowledge of their reactions to triggers.

Interview data revealed that five clinicians, one veteran, and three trusted others said that trusted others could provide information regarding nightmares. In the survey, clinicians rated this topic as a top area of interest and reworded the text message question for trusted others to read, "How often does your Veteran have disturbing or upsetting dreams?" Trusted others were somewhat comfortable answering the question and neither likely nor unlikely to observe it. This is likely because nightmares may only be observed by a trusted other who is able to watch the patient sleep, which is not relevant to the broad trusted other roles defined and represented in the study. Trusted others in this position might toss and turn, wake suddenly, or react to the nightmare. T7 said:

> *"[My husband] had a lot of nightmares. I think there's hardly ever a night that he didn't wake up yelling or screaming." (T7)*

However, nightmares may not necessarily have a visible component. T10, C9, and C10 explained that the veteran might have to verbally express that they experienced a nightmare. C10 felt that the presence of fewer nightmares could be useful information but warned that asking for these types of symptoms could put trusted others in difficult positions. C10 said:

> *"A lot of the re-experiencing, I don't think it would be very helpful to have family members or friends be put in the position where they feel they need to ask about it, or they are not equipped with the training or the skills to bring up those conversations." (C10)*

Four trusted others, VT1, T3, T4, and T8 felt that they could provide collateral information regarding dissociation and flashbacks. VT1 and T3 believed they were able to see dissociation when their veterans checked out with blank stares. In terms of flashbacks, T3 and T8 were not able to see the flashback occurring but had learned what aural and olfactory triggers caused them, and subsequently knew when the flashbacks would happen. T4 was also aware of triggers but indicated that he was able to see his nephew have a flashback which he characterized as a blank stare in a specific, triggering situation. He said:

> *"When it's extremely dry, when he's out in his yard working and he's sweating and he's doing things... I would just sit there and watch him, and it wouldn't take long. You'd just see his blank face and you can tell he's somewhere else. He'll keep mowing the lawn and doing what he's doing. He has no idea how he did it though. You'll talk to him later. He goes, 'I don't remember cutting the grass.'" (T4)*

Some trusted others may be able to report on trauma re-experiencing symptoms, but they are not always readily observable. Trusted others should not be put in a position to directly ask about non-observable symptoms in this category.

### *Avoidance Behaviors*

There is strong evidence that trusted others can successfully report on avoidance behaviors such as avoiding particular situations or actions. In the PCL-5 exercise, identification of avoidance behaviors ranked first, and trusted others reported that it would be extremely likely that they observed this behavior. Through the interviews, six trusted others provided details around their ability to see avoidance behaviors. T1, T7, and T10 said they were able to identify their veteran's avoidance of crowds. VT1 noted that he could see when veterans avoided things they used to like. VT2 shared that she noticed that her husband avoided fireworks. T4 explained that in counseling with his nephew and nephew's wife, he recognized avoidance behavior in his nephew. He recognized the behavior from a story his nephew's wife shared in which his nephew would not respond to her when she knew something was wrong and asked about it. She said, instead of responding, he played video games.

Not only can trusted others see avoidance behaviors but providing responses via the Social Sensing System may fill a gap in veteran self-report. Veterans reported that they believed trusted others were somewhat likely to observe this behavior and were somewhat comfortable with them reporting on it. In the interviews, only V2 shared that a trusted other would be able to identify his avoidance of grocery shopping. Clinicians explained that avoidance behaviors become normalized in chronic PTSD and may be difficult for veterans to detect themselves. As such, a trusted other report may fill this gap and identify avoidance behaviors, particularly those that are problematic in daily life.

Avoidance behaviors are expected to be easily observed by trusted others. However, once in treatment, clinicians also expect that trusted others who may be more sensitive to change, could notice decreasing avoidance in the form of engagement. C4 explained:

> *"Sometimes avoidance has been so long-term with chronic PTSD that [it] becomes a part of [the veteran's] normal functioning. So, it might not be apparent to them. Whereas the partner might more easily see these changes. Like, for years, they haven't been engaging in [something] and now they are engaging in activities with their children or going to the grocery store." (C4)*

Both avoidance and engagement behaviors may be visible to trusted others and are of interest to clinicians. This may be especially helpful as veterans may not be aware of these behaviors.

*Negative Alterations in Thoughts and Mood*

The data suggests that trusted others can observe symptoms associated with negative alterations in thoughts and mood such as feeling isolated, displaying negative affect, and demonstrating irritability and aggression, though not all forms of these are appropriate for the Social Sensing System.

First, clinicians, veterans, and trusted others believed that trusted others would be able to report on increasing or decreasing irritability and anger. C3, C5 C7, C8, C9, and C10 said trusted others would be able to see outbursts, hear shouting, and notice persistent irritability or anger. However, as T8 pointed out, not all trusted others may feel comfortable reporting on this information. Yet, data from two participants suggests that this might also be a symptom veterans struggle to fully notice in themselves. V4 said that feedback from a trusted other could be helpful because while his anger does not seem that bad to him in the moment, he has received feedback to the contrary. Similarly, T5 confirmed that while she can see anger in her husband, he may not always recognize it himself. She said:

> *"Sometimes [my husband] doesn't realize that something's bothering him...until I tell him later on how he reacted or how he acted toward me or the kid- how upset he was. Or if we were in the store and somebody bumped him, he doesn't realize when that switch goes off and he's hollering at someone, he doesn't realize until maybe even several hours later after we've sat down, and I bring it up to him that he acted that way." (T5)*

Participants also believed that trusted others could provide useful collateral information regarding isolation and negative affect. C10 believed that trusted others could identify depressive behaviors while C7 was interested in understanding whether the veteran left their room or the house. Some participants flipped the tone of how trusted others might be asked about these behaviors to be both positive and related to their own relationship with the veteran. C6 and C9 believed trusted others could be asked about connection to and vulnerability of the veteran. For example, was the veteran spending quality time with them? V3 and T4 echoed this sentiment of checking in on a connection with a trusted other by posing questions about the veteran's sex life, if appropriate.

Significant limitations in text message response topics arose in the interview data from trusted others regarding negative alterations in thoughts and mood. There are extreme, observable behaviors in this symptom cluster including harming oneself and others. For example, V5, T4, and T10 discussed the ability of trusted others to report suicidal ideation. VT2 discussed violent behaviors. It is important to note that trusted others, who could be asked to provide feedback, may have the ability and desire to report on these behaviors. However, the Social Sensing System is not intended to manage this type of information which requires urgent intervention.

All participant groups shared that trusted others would be able to effectively report on behaviors related to negative alterations in thoughts and mood. While some of the symptoms may be helpful in providing a more holistic picture of veteran behavior, others are inappropriate for the design of the system.

### *Hyper-arousal*

Hyper-arousal behaviors were determined to be observable by trusted others and of interest to clinicians who ranked two-related questions regarding hyper-vigilance and startle response in their analysis of the PCL-5. Interestingly, veterans believed trusted others were most likely to witness these behaviors while trusted others only believed they were somewhat likely to see them. T4, who provided religious counsel for many veterans, explained that hyper-vigilance can be especially prevalent in veterans:

> *"It's so drummed into them in the military to be hypervigilant, especially those with PTSD, it seems to be always with them. You can be cured of it, but they are hypersensitive to particular vehicles, particular people, sounds, smells, all those different things." (T4)*

Five clinicians also felt trusted others would be able to report on sleep patterns. C5, C8, C9, and C10 said that trusted others who shared a bed with a veteran could indicate whether they had been sleeping better or worse. C4 was interested in a trusted other sharing how long it took a veteran to get back to sleep. T1, T2, VT1, and V2 also noted that trusted others could report on sleep patterns.

### *Other Observations*

Two other areas of observations emerged in the findings. First, four clinicians believed that trusted others could provide collateral information regarding homework practice. C2, C3, C7, and C8 were interested to know if the patient was completing their homework as instructed. C2 wanted to know if trusted others could provide data about barriers to completing homework exercises. She said:

> *"[Collateral information from trusted others] could be especially helpful if a patient is having trouble implementing their homework." (C2)*

Second, four participants that identified as a trusted other or veteran wanted to provide information regarding alcohol and substance abuse. One of these participants, T2, explained that this could also be done in positive manner by reporting on sobriety. She said:

> *"There's impulsive behavior, impulsive drinking, impulsive smoking of a variety that we probably shouldn't speak of...he went to bed sober last night, which was a huge accomplishment, and he slept through the night and didn't have any nightmares, got up, said, I feel great. You have to constantly positively reinforce that. You know, that's a great job, that means you can do it again tonight. You know, you got so much done, I bet you, it felt good...There's got to be a balance because if the person always hears of all the bad things they're doing or how they suck at life, it's just hurting them and that doesn't give anyone any ability to build back their mental health." (T2)*

These additional observations were not originally conceptualized in the notion of the Social Sensing System. While it might be possible to tailor questions in these areas, it could raise issues of trust and privacy. I will discuss this in detail in the discussion section.

### 6.4.3 Social Sensing System Logistics

In this section I discuss the format and cadence of text message questions which could be used through the Social Sensing System.

#### *Text Message Cadence*

Clinicians indicated that text message questions should be sent to trusted others at the start of therapy to determine a baseline, throughout therapy to assess changes, and as a follow-up after therapy concludes to check-in. However, the cadence of questions varied by group and type of program in which the Social Sensing System could be deployed. For the two-week intensive outpatient program, clinicians desired feedback from trusted others anywhere from 3-8 times and were cognizant that asking too many questions too many times could be burdensome. 8 veterans preferred that trusted others provide feedback at least once, with 3 desiring feedback 3-5 times and 3 wanting feedback more than 5 times. All trusted others agreed to provide some feedback; 3 agreed to 1-2 times, 1 individual agreed to 3-5 times, and 6 desired to provide feedback more than 5 times.

In an 8-week therapy program, clinicians desired feedback from trusted others weekly to bi-weekly. 8 veterans indicated that they would want trusted other feedback at least 3 times, with 3 individuals seeking feedback 3-5 times and 5 individuals wanting feedback more than 5 times. All trusted others agreed to provide some feedback; 2 agreed to 1-2 times, 2 individuals agreed to 3-5 times, and 6 desired to provide feedback more than 5 times.

Ranges in responses indicate some similarities between participant groups, however, due to the small number of participants in the survey it is difficult to assert what cadence is most appropriate for all groups.

#### *Feedback Formatting*

Text message questions for trusted others can come in multiple formats including Likert scale response, a yes/no response, or an open-ended/free response. Clinicians preferred the Likert scale response and the yes/no response options best. Eight of 10 clinician participants did not feel that the open-ended/free response would be appropriate, fearing it would invite unwelcome information including irrelevant (i.e., unrelated to PTSD) or sensitive (i.e., suicidal ideation, domestic abuse) information.

Clinicians also stressed that text message questions should be written in a way that will be easy for a trusted other to understand. C7 and C9 said that trusted others may not have heard or know how to interpret terms specific to this realm such as 'hyper vigilance.' Instead, they advocated for the use of plain language. Similarly, C5 suggested adding examples of what behaviors a clinician might find useful to guide trusted others.

### 6.4.4 Social Sensing System Implementation

In this section I discuss how each participant group perceives how trusted other feedback will be used in therapy and expectations around data access and control.

#### *Perceived Use of Feedback in Therapy*

The intent of data collected through the Social Sensing System is for use in the clinical setting. My findings demonstrate that participants believed this data could be incorporated into the clinical setting to gauge veteran response to treatment, validate self-report, and adjust therapy accordingly.

Some participants felt that trusted other feedback provided through the Social Sensing System could be incorporated into the therapy session in shared interface under the guidance of a clinician. Clinicians envisioned using the trusted other feedback in a visual way to demonstrate progress over time; C5, C8, and C10 suggested displaying it in conjunction with self-report graphs such as the PCL-5. Similarly, veterans desired a high-level, visual way to review the data.

Veterans stressed that if they had opted in to using a technology like the Social Sensing System that they would expect that the data be utilized, though they acknowledged incorporating this data into treatment could be challenging. V3 and V2 said this could be especially true early on in treatment when PTSD symptoms were likely to be worse. To ease this challenge, three veterans suggested that there might be a delay anywhere from a week to 30 days in discussing high-level, de-identified feedback with a clinician to avoid negative consequences. V2 said:

> *"I would [want to review this information] in the presence of the doctor...if I was in a negative mood and it was early on in therapy and [I learn] hey, your trusted other is out there saying somethings happened, you know, then I might act out or do something silly." (V2)*

Clinicians envisioned that they would use the trusted other data to verify self-report. While they noted that the data could be used to corroborate self-report, the examples they provided for use primarily focused on discrepancies. Five clinicians said that trusted others may be more sensitive to noticing changes which can be helpful for veterans who may under-report or be locked into an identity of PTSD that causes them to report the same way over time. Trusted other feedback which demonstrates changes in behavior that a veteran hasn't noticed to the same degree could reinforce that treatment is working. C8 explained how they would manage comparing the data and subsequently addressing it in session with the veteran. C8 said:

> *"If it seemed like things seem to be improving according to the veteran and their family then I might comment on it and say wow, your family seems to see improvement to you know? But if it was discrepant, I think I might bring it up with the veteran...[I] would check in [and say] this is what they are reporting, why do you think that is? Maybe there*

> *is a different explanation, like maybe the [trusted other] is mad at [them] for some other reason or...the family thinks they are doing better and they're not. Then maybe we have a discussion around, are you seeing this or not? Is it their own difficulty recognizing their own progress?" (C8)*

Clinicians and veterans said that while self-report could provide additional information, it had limitations that should be considered if being used for clinical purposes. Two clinicians mentioned that trusted others are directly impacted by the actions of veterans and may lack context into the therapy process itself. Five clinicians said that several PTSD symptoms are not necessarily observable due to the nature of the symptom (e.g., flashbacks) or access of the trusted other (e.g., sleep difficulties). This could lead to hearsay reporting or misidentification. For veterans with co-morbidities, this could be even more complicated. T2, whose veteran had TBI, wasn't sure which symptoms resulted from which condition. V7, who did not want to use the Social Sensing System, warned that misidentification of symptoms was serious and real. She said:

> *"One time I went to a bar, and I saw a girl pass out on the ground, and she looked like one of my friends from the military that got raped, and I freaked out. I cried in front of people. I ran to the bathroom. I was not okay. And my 'trusted friend' who ended up really not being my friend...people came back and said that she's talking s*** about you and saying that you're f***ing crazy. And I'm like, I basically had a flashback to one of my best friends in the military getting raped. I don't know how else I would have reacted. I just don't think it's a good idea to have your friends or the people that you love get involved in something like that that they don't understand."*

Given the ways in which participants envisioned text message data be used in session and along with the limitations of self-report, it is unsurprising that clinicians would use this data primarily for additional collateral information to support conversations in session. They said that this could help to further tailor treatment especially by providing data surrounding barriers to engagement and progress over time. Veterans also demonstrated that feedback from clinicians in session could help them understand their progress but might also cause discomfort and negative consequences depending on what was addressed and how.

### *Data Access and Control*

Veterans felt that they owned the text message data submitted by trusted others as it pertained to their mental health. Accordingly, seven veterans expressed a desire to access their data on their own terms. Two veterans wanted immediate access to their data and did not want to wait for a clinician to review it. T3 said that this was important to him because he had been denied access to his health records by the military in the past. V4 said they wanted to be notified when trusted others provided feedback by either understanding the cadence or by receiving a notification. In terms of granularity, five veterans preferred to only see de-identified data whereas V1 believed they should have full access in the spirit of trust and progress. He said:

> *"Everything should be out in the table. When you hide something, or you don't tell people something you don't know what to do about it. If you're not being honest, you're not being open, you're not going to be able to figure out the best way to help somebody." (V1)*

VT1 believed that veterans and clinicians should have access to the same level of data. Rather than giving granular information about sleep patterns, an interface might say "The veteran has issues with sleep" and function as a starting point for conversation. He said:

> *"If a provider comes in and says, 'You didn't sleep six nights last week,' the [veteran is] gonna shut down. And if you give the provider that information, some of them are gonna do that because they're idiots."*

Trusted others also believed that veterans should receive access to the data, and the majority said that this should happen under the guidance of a clinician. Two trusted others differed in their opinion. T4 believed that the patient should choose when accessing the data was best for them. T2 said the veteran should get access before their appointment, however, in this case she was used to her veteran receiving only monthly appointments and felt the Social Sensing System could be a way to stay engaged with treatment. In terms of granularity of the data, trusted others differed in their responses. T3, T4, T5, and T8 were comfortable with the patient seeing what they had reported with their names attached. T10 felt that they would willingly provide access to feedback text data regarding PTSD symptoms such as avoidance behavior but would not want the veteran to know that they had reported on substance abuse. T2 believed all the data should be anonymous. They felt they could use the Social Sensing System to provide more honest feedback than they would normally share with the veteran. T2 said:

> *"I might be a little more apt to be more honest on the app...because I am not saying anything to his face." (T2)*

Some veterans also expressed a desire to control what data was collected, who it was collected from, and where it was stored. VT1 believed that while clinicians could provide limits on what was possible within the Social Sensing System, ultimately the veteran should be able to exercise control in data collection. For example, he believed veterans should have the ability to opt into which text messages could be sent to trusted others. In the same spirit of control, veterans expressed a desire to be able to add and remove trusted others at will. As V6 pointed out, veterans need to choose their trusted others carefully as inaccurate reporting could 'mess up' a session. V2 worried that trusted others might sometimes have ulterior motives or negative feelings toward the individual at the time they were filling out the feedback texts. Similarly, V3 pointed out that trusted others now have a 'say' in mental health appointments and suggested that the veteran should have control to remove them if they felt they did not have their best interest at heart. He said:

> *"How easy would it be to remove somebody if for some reason they were out of your life? Because now they have access – they have a say in your mental health, especially if you got on the wrong foot that week." (V3)*

Only one clinician commented on the possibility of how conflict might affect veteran perception and use of the Social Sensing System. C3 said:

> *"I would think if the person were having really significant conflict with someone, it could be really detrimental to be getting information from that person if the patient knows about it and feels like that person is somehow getting in the way of their therapy." (C3)*

Finally, V3 and VT1 shared their thoughts on data privacy. While V3 trusted that their data privacy would be upheld, VT1 believed that this data should not be stored in any way that attached it to a patient's name. He used himself as an example of what could go wrong. He is a firearms instructor and explained that if individuals like him received negative reports and were stored under his name, there was potential for the government to use these against him negatively to strip him of his Second Amendment rights (e.g., gun ownership).

## 6.5 Discussion

The inclusion of multiple perspectives facilitated through computational systems necessarily raises questions of power dynamics, particularly which perspectives command the most power and attention [48,75,88]. The need to examine these power dynamics when designing new computational systems is essential. As Winner points out in his seminal work, such politics and power are inherent in design and may promote or challenge existing structures of power and authority or social patterns [200]. Recent work by Davis has emphasized the nature of power and politics in the design of medical technologies. She challenges anyone practicing design in this context to consider the following question: How do medical technologies afford embodied relations to health? Davis provides the mechanisms and conditions framework as a way to investigate this question and examine how the design of specific health technologies reconfigure the body, for whom, and under what circumstances [42].

I leverage Davis' mechanisms and conditions framework to examine the political dimensions of the Social Sensing System. In doing so, I reflect on the veteran's existing social structure, power conditions, and cultural norms which may encourage or discourage use of such systems. Currently, there is limited literature which explores the political and power dynamics of technology in the clinical context beyond the typical patient-clinician dyad. Additionally, this work extends Davis' framework to mental health, where therapies (including PE) are rooted in the patient's self-report. I investigate how and under what circumstances trusted other feedback supports, changes, or negates a patient's understanding of the embodiment of their PTSD (i.e., symptom clusters).

Incorporating trusted other feedback into the therapy process highlights a shift in the patient-clinician dyad and stands to affect both clinical decision-making and patient engagement. Davis, who emphasizes power and politics in design, asks: How do medical technologies afford embodied relations to health[42]? I extend this work into the realm of mental health by exploring how and under what circumstances trusted other feedback supports, changes, or negates a patient's understanding of the embodiment of their PTSD (i.e., symptom clusters). Of the 30 participants, 27 wanted to utilize the Social Sensing System as part of the therapeutic process. It is important to note that most of these participants reported the importance of a strong bond between the veteran and trusted other (e.g., open communication, involvement in care). When this bond was present, trusted others were comfortable providing feedback and veterans were open to receiving it in a de-identified, high-level format. While some of the feedback may have been difficult to hear, especially early in treatment, veterans believed it could help them better understand their own behavior. There was evidence from all three participant groups (veterans, clinicians and trusted others) that this feedback could be especially useful in detecting both problematic behaviors which have become normalized as a result of chronic PTSD and progress which may have gone otherwise unnoticed. In this sense, trusted other feedback can support or even change a veteran's relationship with their own mind by causing them to reflect and re-interpret their own behaviors related to PTSD symptoms. It may provide additional insights which support engagement with the therapeutic process by reinforcing that treatment is working.

While trusted other feedback can support patient engagement and understanding of their own health, there are circumstances in which trusted other feedback can negate a patient's understanding of the embodiment of their PTSD. My findings highlight the mixed ability and comfort of trusted others to identify and report PTSD symptoms. Often, this can stem from lack of knowledge or the nature of the relationship between the veteran and trusted other. Trusted other reports may be intentionally (e.g., sabotage due to a fight) or unintentionally (e.g., misidentification) inaccurate. In such cases, the clinician is required to investigate the disparities between trusted other feedback and veteran-self report. The inclusion of such data may undermine a veteran's identity and the sense of trust between the patient and clinician.

### 6.5.1 Analyzing Social Sensing Through the Mechanisms and Conditions Framework

I utilize the mechanisms and conditions framework [42] to analyze features of the Social Sensing System to further investigate how the different features of the Social Sensing System reconfigure the body, for whom, and under what circumstances. I employ the vocabulary provided by Davis for mechanisms and conditions and have italicized each instance of these words for emphasis below.

#### *Selection of Trusted Others*

The selection of trusted others challenges the *cultural and institutional legitimacy* of therapeutic practice and social dynamics by introducing the trusted other. Underlying power dynamics inherent in the patient-doctor relationship in which the clinician is more powerful may complicate the *perception* of the Social Sensing System. Clinicians may not welcome a change in routine, and veterans may feel pressured into using the system if recommended by their clinician. Similarly, veterans may feel pressured to include trusted others who desire to provide feedback even if the veteran prefers they did not. The Social Sensing System *demands* selection of at least one trusted other. For veterans without a developed social support network, the inability to meet these criteria has the potential to compound their sense of isolation. In cases where potential trusted others are already involved in veteran care, the Social Sensing System may support therapeutic efforts by including the trusted other as another source of data. In either case, using the system requires that veterans display vulnerability in *allowing* trusted others to report on their behavior, which challenges the insular lifestyle of many veterans [48]. This potentially incurs a burden upon the trusted other for the outcome of the therapy and the clinician for maintaining the status quo relationship between the veteran and trusted other. Future systems should consider how to maximize veteran autonomy and choice in opting to use social support systems.

### *Symptom-based Reporting*

Trusted other feedback is organized around PTSD symptom clusters (e.g., trauma re-experiencing, avoidance, negative alterations in thoughts and moods, hyper-arousal). Feedback *requests* and *encourages* trusted others to answer questions designed to track the presentation of PTSD symptoms in the veteran and *allows* clinicians to include the feedback in future therapy sessions. The nature of some symptoms (e.g., sleep patterns) *demands* that trusted others be in a position to observe the behavior. The social dynamics of some trusted other/veteran relationships may naturally *refuse* reporting on these symptom clusters. The current design of the Social Sensing System which uses a specified list of questions *discourages* trusted others from reporting on non-observable symptoms. The design also *allows* trusted others to report upon symptoms that veterans struggle to fully assess in themselves but *refuses* reports of extreme behaviors such as suicidal ideations which would require urgent intervention. Finally, the Social Sensing System currently *refuses* reporting of data not related to symptom clusters, such as the use of alcohol. While clinicians reported this data would be useful, its inclusion potentially changes the *perception* of power between the trusted other and the veteran who may feel as if they are being judged. Further research is required to understand the trade-off between use of the data in therapy and the effect on the veteran/trusted other relationship. Future versions of this system could include resources feature available to trusted others, where they can be directed to help-lines or other support tools.

### *Valence and Implementation of Feedback*

Clinical wording of the questions, asking "how much avoidance" or "how hyper-vigilant" a patient appears to be naturally *encourages* a critical assessment of progress. This directly works against the intent of showing patients their improvement over time. Rather than emphasizing the negative, future designs may consider *encouraging* reporting on positive observations (i.e., engagement rather than avoidance). This still demonstrates change over time which was important for clinical decision-making and has been demonstrated in patient engagement [48].

The implementation of feedback in therapy may *discourage* veteran patients from engaging with their trusted others in order to avoid negative feedback. For veterans to *perceive* trust in the Social Sensing System, the findings suggest that veteran patients review anonymous data which *discourages* veterans from determining who said what. However, the design has no minimum number of required trusted others or cadence for the release of the data, it would not be impossible to identify responses and could result in unintended negative consequences between the veteran and trusted other. If veterans do not have what they {*perceive*} to be sufficient control, access, and privacy over their data, they may question the *cultural and institutional legitimacy* of the Social Sensing System. This threatens to decrease the veteran's status and power. In addition, the Social Sensing System *allows* use of the data by clinicians in whatever form they desire. It does not currently consider their *dexterity* in their craft or in using the system. It reinforces the existing patient-clinician power structure. Any inappropriate use of the feedback directly contradicts the intended effect of the design. Future designs must consider how to navigate varying levels of clinician competency as well as a sense of control and safety over mental health data for veterans who may be particularly distrustful.

### 6.5.2 Limitations and Future Work

It is important to highlight that self-selection of veterans who already included trusted others as well as trusted others who were active participants in veteran care may have influenced the results of this research. However, this leads me to conclude that this system is perhaps best suited for individuals with stable relationships. In addition, this population is not necessarily representative of all gender, regions, or micro-cultures within the veteran community or of varying levels of clinical expertise. Future research should consider how concepts such as the Social Sensing System function during actual therapeutic practice and if veteran, trusted other, and clinician perceptions differ in the reality of using such a system. In particular, how has the system affected a veteran's relationship with themselves as well as others in the circle of care? How can data collected through the Social Sensing System be visualized and used on the ground in a trauma-based care setting? Finally, future studies might consider incorporating both human and non-human intermediaries to provide a more holistic picture of mental health for veterans with PTSD and how this can be leveraged to support clinical decision-making and patient engagement.

## 6.6 Design Implications

In this section, I present design implications as a result of my findings and analysis of the Social Sensing System through the mechanisms and conditions framework.

### 6.6.1 Customize the Cadence of Feedback

Technologies can independently survey stakeholders to determine the desired cadence for text message deployment and release of the data. This may provide balance and manage expectations among the three groups. It may also reduce burden on trusted others, allow clinicians to determine how often they would want to incorporate feedback into their sessions, and provide reassurance that veterans have control in the process.

### 6.6.2 Emphasize the Familiar and Positive

Despite the initial design around the PCL-5, it is clear that obtaining accurate or what are perceived to be accurate reports from trusted others may be challenging. Trusted others may misidentify symptoms and relationship issues may impact reporting. Rather than identify symptoms, trusted others may be able to report on their relationship to the veteran (e.g., How connected do you feel?) or provide feedback in positive terms (e.g., How engaged are they?)

### 6.6.3 Veteran Control of Trusted Other Participation and Content

A future interface should allow veterans to choose and remove trusted others, if necessary. Clinicians should have visibility into this process. Clinicians and veterans may also 'co-design' the text message experience by choosing questions they would find useful and appropriate together.

### 6.6.4 High-level Feedback from All Parties

Given that clinicians did not want data surrounding serious topics reported via text message and did not suggest the need for follow-up on any text messages with trusted others, they may not need access to identifiable data. Instead, clinicians and veterans can have access to the same de-identified data through a shared interface.

### 6.6.5 Gauge Relationship Impact

The Social Sensing System should consider deploying regular assessments to the veteran and trusted other to gauge any changes in their relationship as a result of the Social Sensing System. Based on responses, the manner in which the Social Sensing System is used for this patient (i.e., how often feedback texts are sent, feedback text content) might be adjusted or the program terminated.

## 6.6. Conclusion

HCI is increasingly concerned with enhancing therapy for mental illness by creating supportive technologies around patient engagement. I extend this work by investigating how technology can leverage useful feedback from trusted others to support the therapeutic journey. This study makes the following contributions. First, I offer one of the first investigations of social support (i.e., trusted other) feedback for use in clinical practice for veterans. Second, I provide insights into perspectives of clinicians, trusted others, and veterans with PTSD and provide a conceptual design of the Social Sensing System for PTSD. Third, from gathering these insights, I provide an investigation of power and politics of such systems using the mechanisms and conditions framework [40].

# Chapter 7: Conclusion

In the previous chapters, I have detailed four research studies in which I lay the foundation for design by understanding the care ecologies of veterans, seek validity of an initial concept through testing with clinicians, and complete an in-depth investigation of how human (e.g., trusted others) and non-human (e.g., sensor-captured patient generated data) intermediaries can be incorporated into a shared interface to support patient engagement and clinical decision-making. I began this dissertation by stating “Understanding veterans’ care ecologies and designing user-centered interfaces can improve clinical decision-making and patient engagement during evidence-based therapy for PTSD.” I ask the following research questions: How do we characterize veterans’ care ecologies as they undergo clinical treatment for PTSD? What role can human and non-human intermediaries play in supporting patient engagement and clinical decision-making during clinical therapy for veterans with PTSD? What elements of design are essential for shared, user-centered interfaces which seek to support clinical decision-making and patient engagement in the context of veterans with PTSD? In the sections below, I address this thesis statement and each question. I then share areas for future work and a conclusion.

## 7.1 Characterizing Veterans’ Care Ecologies

In Chapter 3, I describe veterans’ care ecologies as they undergo clinical treatment for PTSD. This study lays the foundation for subsequent ideation, prototyping, and research. As this work developed and each additional study occurred, my understanding of the veterans’ care ecologies deepened. In this section, I will provide a summary of each layer of veteran’s ecology of care as presented in Chapter 3. Then, I will highlight any new characteristics of the care ecology uncovered in the subsequent studies.

### 7.1.1 Veterans with PTSD: Limitations of Self-Report

Veterans, who are at the center of the ecology of care, face a variety of challenges when engaging in clinical therapy for PTSD. In Chapter 3, I describe how Veterans may struggle to engage in therapy for a variety of reasons. First, their military identity, which favors hyper-masculine behaviors such as strength, and stoicism, can pose a barrier to seek and receive care. Second, PTSD can make it difficult for veterans to recognize their own symptomatic behaviors or indicators of progress in therapy. Third, veteran self-report can be problematic due to issues of remembrance and bias. This may be exacerbated in veterans who suffer comorbidities such as traumatic brain injury (TBI). Self-report may be bolstered by using applications such as PE Coach to collect metrics associated with evidence-based therapy such as SUDs; these may be systematically collected and visually depict a decrease in symptoms displayed over time (e.g., Excel graph). In Chapter 6, I provide additional detail on the limitations of veteran self-report, sharing how veterans, trusted others, and clinicians acknowledge that veterans can become accustomed to problematic behaviors. For example, avoidance and anger may seem normal, when in fact, it is a symptom of PTSD. Furthermore, I share instances where veterans who have flashbacks or nightmares may have poor recollection of what occurred. In Chapter 5, I describe how clinicians treating patients during the pandemic use tools such as video calling and virtual worksheets to collect self-report information.

Later, I also learned that self-report must be considered within the context of the individual circumstances. In Chapter 5, I explain how patient practice (and there by self-report) of therapeutic exercises is highly individualized. Clinicians manipulate the PE therapy protocol to meet the unique patient needs. Every patient calibrates their own SUDs unique to their own experience. The way they practice their homework exercises is personalized as well, particularly early on in therapy. For example, if a veteran tends to become over-aroused, the clinician may allow the patient to perform behaviors that would not otherwise be appropriate for the exercise. Despite having a manualized protocol for PE therapy, the actual patient practice varies based on their unique needs.

### 7.1.2 Clinician (Community)

Clinicians are a core part of this research and a necessary part of the veteran's care ecology. In Chapter 3, I explain how clinicians and patients must first develop a sense of trust for the veteran to become vulnerable and share openly. This may be easier for clinicians with experience in the military. Once veterans are more open to communicating, clinicians utilize their intuition in individual and group sessions to interpret data (self-report) and guide treatment. In the first study, I had focused on clinician-matching and developing a positive relationship. While I do not discount the need for a compatible relationship, this was too simplistic a view on the role of clinicians in the veteran care ecology.

As studies progressed and I spoke to more clinicians and patients, it became clear that there was a distinction in how clinicians practice. First, some clinicians were considered novice at their craft. Patients described these individuals as lacking ability or knowledge around their treatment. Several patients felt they had been treated by novice clinicians who had done a poor job. In their opinion, it was more than a mismatch. It was lack of skill. Expert clinicians, who participated in Studies 2-4, explained that novice clinicians can struggle with certain aspects of evidence-based therapies. They may worry they will push their patients too far. Furthermore, they may not have the confidence and ability to manipulate the protocol to meet patient needs.

In addition, in Study 1, I detailed how clinicians utilized a variety of disparate data sources to inform their understanding of patient progress through treatment. In Study 2, I confirmed that this current workflow can be time consuming and cumbersome for clinicians who are seeking better ways to ingest data and make treatment decisions.

### 7.1.3 Trusted Others (Family and Community)

Veterans may have informal care partnerships with veteran and/or civilian family and friends as they engage in clinical therapy for PTSD. These individuals can see veteran behavior through in-person or digital interactions. Veterans may rely on these individuals for real-world support including help with symptom management, medication adherence, and scheduling appointments. Some were less involved in medical tasks and treatment but could act as social support if needed. Veterans expressed that they were able to share more openly with other veterans due to a shared military culture. However, not all civilian or veteran relationships were characterized positively. Trusted others were eager to participate in care and felt they had or were able to provide useful information to clinicians. Clinicians already used trusted others as a part of veteran care in some capacity but explained that trusted other feedback was subjective and that including trusted other perspectives might worsen violence, aggression, or cause damage to an already fragile relationship.

In Chapter 5, I investigate the use of trusted others, what they can see, and how they can participate as a formal member of the veteran care ecology. Two key lessons emerged. First, it became clear that trusted others are not always part of a care ecology. Veterans with PTSD may not have anyone who regularly interacts with them or may not have more than one person. Even if a veteran does have a spouse or child, and the relationship is not outwardly negative as described in the first study, they may not openly share or involve those individuals in their care. Despite this, trusted others were eager to participate and share what they knew with clinicians. Second, trusted others can observe a variety of behaviors related to PTSD. Clinicians were open to receiving most of this information in a constrained format (I.e., closed questions, limited number) and most veterans were open to trusted others providing this feedback. However, some trusted others noted that they were able to identify extreme behaviors such as suicidal ideation. Clinicians were not open to receiving this feedback from trusted others through the means of the Social Sensing System.

### 7.1.4 Society and Environment

In the first study, I provided details regarding clinician practice to treat the electronic health record as a legal document. They only document what is required by law to protect the patients. Similarly, patients expressed mistrust of the United States government, fearing they would use their data inappropriately if it were accessible. In Study 3, this fear of data misuse was again confirmed by veterans.

In Study 3, three new key characteristics relevant to the environmental layer of the care ecology emerged. First, because the research occurred during the COVID-19 pandemic, clinicians were especially interested in the environment of a veteran with PTSD. For many clinicians, this was the first time they were able to capture a glimpse into their home or work life via video sessions. They were familiar with backgrounds, sounds, and individuals who might be present. Second, this research highlighted the significant exchange of language between the clinician and patient in evidence-based therapy programs. The quality of this language should theoretically increase over time as part of PE and is currently captured through voice memo recordings or PE Coach on the patient's mobile device. Third, one clinician highlighted that some veterans may lag behind in trends in technology adoption. Even if they owned smartphones, they may not be on unlimited data plans or high-speed networks.

## 7.2 Implications for the Inclusion of Human and Non-Human Intermediaries for Clinical-Decision Making and Patient Engagement

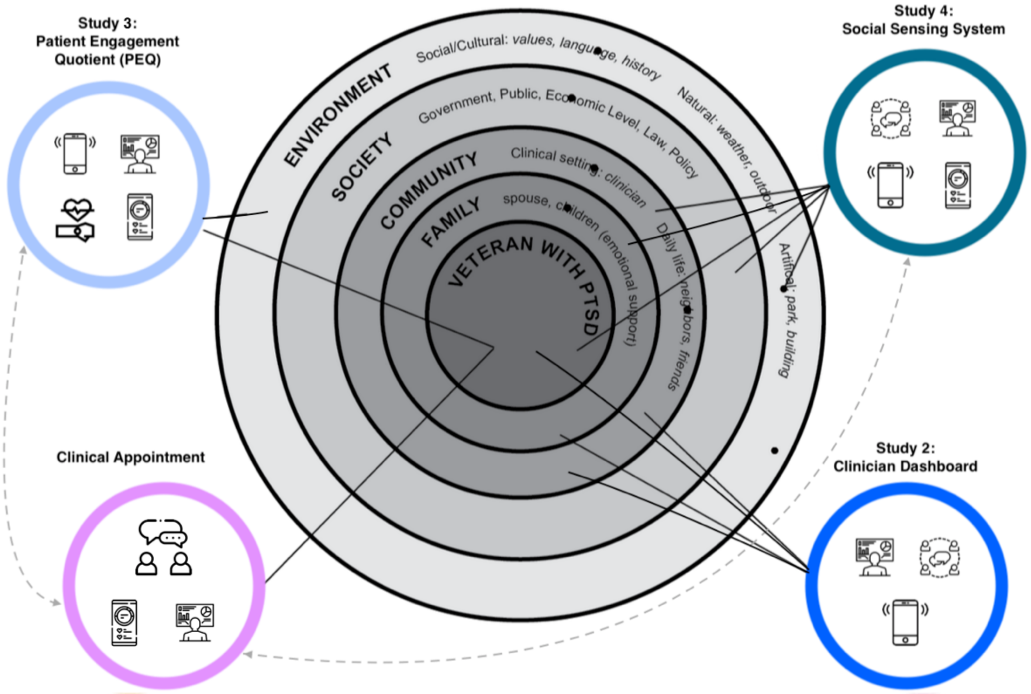


*Figure 15: Veteran's Care Ecology with Respect to Bronfenbrenner's EST and layers involved in each study*

The care ecology of a veteran with PTSD lays the foundation for determining which human and non-human intermediaries can play a role and in what way to improve clinical decision-making and patient engagement during evidence-based therapy for PTSD. In this section, I review the cyclical notion of patient engagement and clinical decision-making. I then summarize evidence in Chapters 3, 4, and 5 that demonstrate how I've conceptualized the use of human and non-human intermediaries can improve both patient engagement and clinical decision-making.

Patient engagement combines a veteran's knowledge, ability, and desire to manage their own mental health through interventions that aim to increase health outcomes in a patient-centered manner. It is crucial for continued performance in therapy and successful outcomes. Patient engagement affords veteran-patients personalization of care, access to data, and agency. Patient engagement feeds into clinical decision-making and vice versa. This is an unending cycle throughout therapy. For example, any data collected by patients can be used to improve clinician understanding of patient performance in exercises, inform conversations between the patient and clinicians, allow the clinician to tailor treatment to meet the needs of the patient, and provide space for patient agency and understanding of clinical treatment.

I explore how the non-human intermediary of sensor-captured patient-generated data via mobile phone and commercial wearable might improve patient engagement and clinical decision-making during evidence-based therapy for PTSD in veterans. The PEQ by nature of its design provides the veteran with a personalized measure of their performance in the imaginal exposure exercise each time they complete it in session under the guidance of a clinician and for homework. This provides the veteran with customized knowledge regarding their performance. Unfortunately, due to recruitment difficulties with the pandemic, I was not able to gather the veteran perspective on the patient-facing mobile application. However, the majority of clinicians who reviewed the concept felt that veterans should have full access to the PEQ data collected and imagined they would have the agency to discuss what they saw in-session with the clinician. Some clinicians felt that they would provide patients with access before an appointment as well. Clinicians felt that this could help veterans understand areas for improvement and highlight areas of progress in a clear way with data that could be considered more objective. However, clinicians did warn that some veterans might become “hung up” on the scores they received which could be a detriment to patient engagement.

Clinicians agreed that they would find the PEQ data useful for clinical decision-making. As clinicians aptly pointed out, this is useful supplemental data and that exposure therapy and conducting imaginal exposures already works without PEQ. The goal of PEQ as a non-human intermediary is not to replace the expertise of the clinician or to replace their intuition. Instead, it is meant to augment their decision-making to the extent of their choosing. Clinicians believed that PEQ could confirm information they already knew (e.g., they live in a noisy environment), uncover new information (e.g., they are using their phone as a distraction during homework), and foster communication between themselves and patients to determine how to create an actionable pathway for the patient to move toward recovery. However, this ability to improve clinical decision-making may be unique to expert clinicians. I discuss how novice clinicians may struggle to interpret and utilize information gathered from PEQ, perhaps undermining patient self-report and placing too much emphasis on treatment adherence, which has been criticized from the lens of patient engagement.

In Chapters 4 and 6, I investigate how human intermediaries known as trusted others can provide feedback via text message regarding patient behavior in the real world. In this study, I was able to obtain patient perspectives on the use of such a system. While self-selection bias could have influenced the study, the response from veterans on using this system was largely positive. The majority felt that use of the Social Sensing System could help them understand their own behavior during therapy. Veterans noted that they struggled to see certain behaviors in themselves and how those behaviors impacted others. While this feedback could be helpful, most veterans did share they preferred to receive the feedback at a high-level in an anonymized fashion. Furthermore, some veterans explained that this type of feedback feature would be best suited for a treatment program with a longer time frame so that feedback could be presented in aggregate in a delayed fashion. Otherwise, they might change their behaviors to avoid trusted others for fear of being watched or reacting in a negative manner. Veterans also worried that trusted others could utilize the text messages in a vengeful way and felt it would be important to control who could provide reports to clinicians and when. The Social Sensing System provides a platform for improving patient engagement but must be curated in such a way that the veteran feels as though the feature provides significant agency and ability to use the data in session with a clinician.

Clinicians felt that the Social Sensing System could improve clinician understanding of veteran behavior throughout the course of therapy. Some clinicians wondered if trusted others could be more sensitive to noticing changes in veterans, both positive and negative, which could inform their clinical decision-making and subsequent conversation with patients. They did, however, note that they would be cautious about placing too high a significance on trusted other reports. They explained that while it offered another perspective, it was important to remember that it was likely from someone who was not trained to recognize PTSD symptoms and who might be directly affected by the veteran’s behavior. Again, this study, which was conducted with expert clinicians assumes that the data collected will be interpreted and utilized in a manner that fosters a sense of trust and communication between the clinician and patient. Patients were concerned that novice clinicians might use data in a way that would negatively impact the relationship. They questioned whether clinicians ought to have a granular level view of the data or if a high-level overview like a patient might receive would be sufficient for the purposes of informing clinical decision-making.

## 7.3 Implications for Designing Shared Interfaces for Evidence-Based Therapies

In this section, I discuss what elements of design are essential for shared, user-centered interfaces which seek to support clinical decision-making and patient engagement in the context of veterans with PTSD. This section presents a summarized version of all design implications throughout this body of work.

### 7.3.1 Leverage Military Culture in an Assets-based Approach

Military culture cannot be separated from the veteran identity. Accordingly, embracing the military identity in an assets-based approach [118] can support patient engagement. For example, technologies can provide personalized data and measures of progress in terms consistent with military identities. In Chapter 6 I discuss the importance of highlighting positive feedback from trusted others to demonstrate strength and progress rather than emphasizing negative feedback or areas of weakness. Similarly, embracing the military identity can support clinical decision-making by influencing the speed and volume in exchange of data during therapy. In Chapter 3, I discuss how veterans are more likely to disengage with treatment when they do not develop rapport with clinicians. Accordingly, embracing the military identity, future designs may be able to guide and educate clinicians in cross-cultural competency. Interfaces may provide conversational prompts which serve to establish understanding between civilians and veterans or assist in matching clinicians or provide suggestions for appropriate clinician and patient matches.

### 7.3.2 Balance the Perspectives of Human and Non-Human Intermediaries with Self-Report

Currently, veteran self-report is the predominate source of data in evidence-based therapy for PTSD. My research, despite investigating the inclusion of human and non-human intermediaries, does not suggest that this change. Rather, human and non-human intermediaries should be considered as supplemental sources of information which can provide additional context and information. Like self-report, these sources of data are subjective and must be considered as such. For example, in Chapter 6 I discuss how reports from trusted others may not be accurate or may not be perceived as accurate by patients, causing a possible negative impact on patient engagement. Shared interfaces must carefully consider how to uphold self-report as the core source of data when others are available as well as to collect and display data appropriately from each source. In the context of trusted others that trusted others report on their relationship to the veteran (e.g., How connected do you feel?) and provide feedback in positive terms (e.g., How engaged are they?) rather than reporting on symptoms. This will be crucial for maintaining patient agency, a key component of patient engagement. Furthermore, while supplemental information can improve clinical decision-making, it may also be used in a detrimental way by novice clinicians who may struggle to interpret or approach using this information in a productive way to promote patient engagement as described in Chapters 5 and 6.

### 7.3.3 Promote Patient Safety and Control of Data

My work investigates the collection of personal and potentially sensitive data regarding veteran mental health as they participate in evidence-based therapy for PTSD. In Chapter 3, I discuss veteran mistrust of government use of data and how clinicians avoid documentation of what is not legally required in the EHR. Again, in Chapter 6, the need for control of one’s own data and considerations for the security of that data emerged. In order to promote patient safety and control of data future shared interfaces should consider a variety of factors. First, in chapter 3 I describe how shared interfaces may benefit from being created and maintained by a non-institutional authority to protect veteran mental health data and instill confidence in the collect of data by veterans. These concerns were echoed in both Chapters 5 and 6. Trust in the system could improve patient engagement and improve clinical decision-making by allowing clinicians to view and manipulate data in an interface which they are not presently able to do. Second, data can be collected in ways that are abstracted or ephemeral in nature. For example, in Chapter 5, passive sensors collect number and duration of phone calls but not the content of those phone calls. Third, veterans should have the ability to turn on and off the use of data collection by human and non-human intermediaries. In Chapter 6, I describe how veterans should have the ability to include or remove trusted others at their discretion. Patients should also have the opportunity to decline transmission of the data from any homework session recorded to protect their privacy. This will protect patient agency, and if these decisions are made in conjunction with a clinician or at least made visible to the clinician, it can provide additional information relevant to clinical decision-making.

### 7.3.4 Consider Customization

Shared interfaces should accommodate the unique health needs of each patient and the workflow of clinicians. When possible, variations in data collection, access to data, and the display of that information should be considered. In Chapter 5, clinicians articulated specific preferences for data streams, data access, and how they would approach the use of this data in-session with patients. Allowing customization would allow for improved clinical decision-making by tailoring interfaces to display these preferences and disregarding superfluous information which could distract clinicians. Similarly, in Chapter 6 I describe how the cadence of collecting and displaying trusted other feedback should be determined by clinicians, patients, and trusted others together to manage expectations and determine what would be most useful to support clinical decision-making and patient engagement. In Chapters 5 and 6, clinicians expressed a desired to have some control over patient access to data. They warned that some patients may fixate on data presented in a shared interface, which could have a negative impact on patient engagement.

### 7.3.5 Determine Data Access

In the context of this work, there was reasonable evidence that clinicians and patients may be able to have the same level of access to data in some cases. However, this may be due to the nature of how human and non-human intermediary data was conceptualized and presented specific to this case. In Chapter 6, clinicians did not want data surrounding serious topics reported via text message and did not suggest the need for follow-up on any text messages with trusted others. It is reasonable to assume that they may not need access to identifiable data. Instead, clinicians and veterans could have access to the same de-identified data through a shared interface to improve clinical decision-making and patient understanding of their own behavior. Similarly, in Chapter 5, several clinicians indicated that patients should have access to all their own data as a principal of trust. Most did not believe they ought to hide anything from their patients. However, some clinicians pointed out that some patients can become fixated, and that this could negatively affect patient engagement. I hesitate to say that patients and clinicians should always have equal access to data. Instead, researchers and designers should consider the type of data being collected, the possible impacts on clinical decision-making and patient engagement, and to make determinations about the level of granularity that is needed to effectively support each.

### 7.3.6 Acknowledge Limitations of the System

While the practice of evidence-based therapy may benefit from the introduction of technology and shared-interfaces, it is important to note that this therapy already works reasonably well without it. As such, it is important to note that these technologies will not benefit every clinician or patient. Use of such technology should be considered on a case-by-case basis and evaluated often throughout its time of use. In Chapter 6, I discuss how the Social Sensing System should consider deploying regular assessments to the veteran and trusted other to gauge any changes in their relationship as a result of the Social Sensing System. Based on responses, the manner in which the Social Sensing System is used for this patient (i.e., how often feedback texts are sent, feedback text content) might be adjusted or the program terminated. Similarly, regular check-ins with patients and clinicians could be developed for the use of a larger system to determine if the technology is truly beneficial. If it is not supporting patient engagement and/or clinical decision-making, adjustments can be made or use of the shared interface terminated.

## 7.4 Future Work

There is much work to be done in the field of HCI for mental health, particularly around the use of shared-interfaces and inclusion of human and non-human intermediaries. In this section, I will detail specific areas which merit additional investigation that arose during my dissertation.

### 7.4.1 Using Predictive Power on Data Collected by Human and Non-Human Intermediaries

The collection of data by human and non-human intermediaries about veteran behavior and their intended subsequent use in appointments by veterans and clinicians provides measurable data that was previously unavailable. This high exchange of data between clinician and patient for evidence-based therapies could be leveraged to investigate a variety of patterns.

First, it may help to uncover specific segments of veterans and clinicians based on behavioral attributes. This could assist in better veteran and clinician matching. Second, after significant data has been collected, it may be possible to predict challenges and outcomes in therapy, allowing for clinicians to respond proactively over the course of treatment. Third, the language collected in imaginal exposure exercises as described in Chapter 5, could be explored using natural language processing. As I discuss in that chapter, clinicians probe patients for more descriptive language throughout the course of treatment. Future interfaces could perform similar personalized assessments of imaginal exposure exercise language and provide feedback to both patients and clinicians. Such a shared interface feature may help guide conversations between expert clinicians and patients; it could also provide guidance and feedback to novice clinicians in training to reinforce the practices of exposure therapy.

### 7.4.2 Defining and Measuring Patient Engagement

In the field of HCI there is growing interest in understanding and designing to improve patient engagement, yet this term is lacking consistency. As discussed in the introduction, there is no agreed upon definition [83,185] or way to measure patient engagement [136,185]. I recommend three paths forward toward defining and measuring patient engagement in HCI. First, an effort could be made to establish a high-level universal definition and characteristics of patient engagement in HCI, much like meta-analysis done in the healthcare field at large [83]. This has already been done to review measurement of patient engagement[136]. Second, due to the human-centered nature of HCI, I can also imagine an argument that rejects the idea of a universal definition of patient engagement in favor of more granular definitions that rely on specific populations (e.g., US veterans), conditions (e.g., PTSD), technological medium (e.g., inclusion of human and non-human intermediaries), and/or the type of care (e.g., evidence-based therapies). For example, patient engagement in the Global South for depression in an online peer support group may look quite different than patient engagement in veterans with PTSD in evidence-based therapy. Instead, patient engagement may be better defined within specific populations (e.g., US veterans), conditions (e.g., PTSD), technological medium (e.g., inclusion of human and non-human intermediaries), and the type of care (e.g., evidence-based therapies). Articulating these patterns and establishing a comparison would provide a view of patient engagement that is not yet present in the field. Third, patient engagement could also be explored in terms of the unique characteristics and needs of a particular individual[136,185], determining what patient engagement means in a hyper-targeted manner. Study 3, which measures the patient's performance in each session, is an example of how we might begin to think of this hyper-targeted approach. Future research could consider how to determine these unique characteristics beyond sPGD and into other mental illnesses (e.g., depression), technologies (e.g., social media), and chronic conditions (e.g., congestive heart failure).

### 7.4.3 Creating an Instrument to Measure Perceived Usability in Patient-Clinician Interfaces

Another area which merits additional exploration is the measurement of perceived usability. In planning the study for PEQ, I struggled to find an appropriate instrument to measure perceived usability in a shared interface for patients and clinicians. I began by reviewing general perceived usability surveys including the System Usability Survey (SUS) [8], the Post-Study System Usability Questionnaire (PSSUQ) [114], the Computer System Usability Questionnaire (CSUQ) [115], the Suability Metric for User Experience (UMUX) [115], and the Technology Acceptance Questionnaire (Post-Study)[132]. These scales effectively addressed perceived usability but are not specific to topics relevant to health technologies. Accordingly, I then reviewed health-specific instruments including the Patient Engagement Scale (PHE) [72], mHealth App Usability Questionnaire (MAUQ) [215], Health Information Technology Usability Evaluation (Health I-Tues) [168], and Twente Engagement with eHealth Technologies (TWEETS) [99]. The health-specific instruments that I reviewed for potential use did provide health-specific questions on utility and usability but did not account for patient-clinician shared interfaces, acknowledge differences in education and literacy, account for disruptions in power balances (e.g., additional perspectives, patient access to data, expectation to have a conversation about data in session). Ultimately, I chose to use a generalized usability survey in combination with a semi-structured interview to meet my needs for Study 3.

There may be opportunity to create a perceived usability for shared health interfaces. In order to address this gap, I had planned to create suggestions for such a survey using magnitude coding [224] on clinician and patient transcripts from Study 3. Unfortunately, due to the COVID-19 Pandemic, I was unable to include veterans in that study and did not obtain the data needed to perform such an analysis. Future research should consider building a survey that articulates how to assess perceived usability in shared interfaces between clinicians and patients. I believe based on my empirical experience with this body of work that a future survey could accounts for differences in education and ability to interpret health data, power dynamics in the patient-clinician dyad, technical competence, and type of interface (e.g. clinician browser-based dashboard, patient using mobile application).

### 7.4.4 Designing for Veterans Not Included in this Dissertation

The work of this dissertation considers how to design for veterans with PTSD. This is a stigmatized group that is disproportionately affected by PTSD [221] and experiences high dropout rates from treatment [138]. While providing tools to support clinical decision-making and patient engagement is important, there is more work to be done in terms of considering how to best serve the wide range of veterans with PTSD present and in need of care in the United States today.

My work explores how shared interfaces might support clinical decision-making and patient engagement in a very particular context. My work focuses on veterans who have access to gold standard treatments for PTSD such as PE therapy, access to technology such as a smartphone with a substantial data plan and FitBit, and expert clinicians. However, the reality is many veterans may not have the privilege of accessing one or any of these. Future research can explore how future shared interfaces can support patient engagement and clinical decision-making for PTSD treatments in additional contexts including telehealth, other evidence-based treatments or combination treatments typically delivered through agencies such as the VA, and/or through less expensive means of data transmission (e.g., less data used on monthly data plan).

Furthermore, while my work focuses on veterans with a serious mental illness, the features of the system I describe throughout this work are aimed at serving those who may have more positive relationships with clinicians, themselves, and others. Throughout this work, it became clear that this system cannot serve all veterans with PTSD. Instead, it will work well for those who may not “over think,” want to be engaged in therapy, have limited comorbidities, and have positive and supportive relationships with trusted others. Yet, the most vulnerable veterans with PTSD may be those who have especially severe PTSD symptoms which may cause extreme circumstances such as isolation or suicidal ideation. Future research should seek out solutions that serve these individuals.

Similarly, in Study 1, I introduce the notion that there are sub-cultures within military culture. My work has not explored how these sub-cultures could be incorporated through assets-based design or otherwise. Future work could determine what it might mean to design for specific sub-populations including gender, race or ethnicities, service era, among others.

### 7.4.5 Extending the Use of Similar Systems Beyond Evidence-Based Therapy for PTSD

Evidenced-based therapy is guided by patient self-report and clinician intuition. Most evidence-based clinical treatments for chronic mental illnesses such as PTSD do not collect data between clinical sessions. Yet, most of the treatment occurs outside of the clinical setting through homework exercises. The additional collection and display of such data could support patient engagement and clinical decision-making for a variety of mental health treatments and chronic illnesses. I have presented six high-level design implications which should be considered when developing shared interfaces for patients and clinicians that include data collected by human and non-human intermediaries. Future systems should be built upon the notion of patient-centric care and consider leveraging their culture, promoting agency in one's own treatment, and ensuring safety and customization to meet patient needs. Future shared interfaces of this nature can consider the patient-clinician dyad and how the introduction of this type of technology may affect this dynamic. Furthermore, they should consider how to support clinicians with a range of expertise and decide what role clinicians will play in data access and customization for themselves and patients. These shared interfaces for patients and clinicians that include data collected by human and non-human intermediaries must carefully consider the balance of power between patient-self report and the inclusion of these additional perspectives as well as how they might be incorporate and utilized in the clinical setting. Additional research on the ground for PTSD and for other chronic conditions can reveal more design implications and practices for how this could be done in real-world clinical practice.

### 7.4.6 Leveraging a Feminist Ecological Approach to Explore Future Designs

In this work, I leverage Bronfenbrenner's EST as a basis for considering how to craft an ecological design for veterans with PTSD. Applying this approach consequently forces a designer to not only consider the individual in "user-centered" design but the entire sociotechnical system (e.g., community, technology, culture, politics, etc.) that surround that user and inevitably impacts the user whether passively or actively. Furthermore, I combine EST with other feminist theories that consider the roles each entity plays in the sociotechnical system as well as the power and politics in these relationships (cite Haraway, Haraway, and Davis). Future work can operationalize this "feminist ecological approach" with key processes and tenants of design that designers and researchers should consider.

A feminist ecological approach lends itself well to the realm of health as demonstrated by this dissertation. This approach necessarily considers the complex nature of care which includes formal and informal care partnerships as well as human and non-human intermediaries, care activities inside and outside of the clinical setting, the role of culture, as well as the power dynamics associated with existing and future care designs.

However, this approach could be applied in  a variety of other scenarios where the "user" sits at the center of a complex sociotechnical system where power dynamics should be considered. For example, this approach could be applied in the realm of business to consider designing for employees. Using a feminist ecological approach, one could explore the ecological system that surround employees (e.g., specific business culture, other individuals including employees, customers involved in their work, organizational structure, cultural movements, etc.) as well as the power dynamics inherent to this unique sociotechnical system surrounding the employee(s). Understanding this feminist ecology could provide a clear understanding of user requirements for future designs (technological or not) and provide a framework for speculating or evaluating how the introduction of these designs impacts the user.

### 7.5 Conclusion

The delivery of evidence-based therapy for is constrained by data collected from patient self-report and clinician. However, many activities occur outside of the clinical office setting. Accordingly, clinicians need methods, tools, and data to efficiently track, assess, and respond to mental health needs while patients need tools that provide feedback to optimize their therapeutic exercises and increase engagement. At the beginning of this dissertation, I presented the following thesis statement: “Designing user-centered interfaces for veteran care ecologies can support clinical decision-making and patient engagement during therapy for PTSD.”

In order to investigate this thesis statement, I first detailed the care ecologies of veterans with PTSD, identifying the human and non-human intermediaries involved in their circles of care as well as barriers to care and future design opportunities. Leveraging this information, I explored how a clinician dashboard for PTSD, sensor-captured patient generated data, and feedback gathered via text message from trusted others (e.g., friends, family) could be designed into a shared interface and support clinical decision-making and/or patient engagement. I discovered that the four studies presented support my thesis statement in specific contexts. In Studies 2 through 4, my participant pool consisted of highly trained clinicians who were experts in the field of PE therapy. However, in Study 1, 3, and 4, participants voiced concerns that such data might influence clinical decision-making, but perhaps not in a positive way. Similarly, in Studies 3 and 4, participants explained that data collected from human and non-human intermediaries could help or hinder patient engagement depending on the veteran’s relationship with others and their desire and ability to productively incorporate non-human data streams into treatment. Accordingly, I conclude that interfaces such as those described in this dissertation support clinical decision-making and patient engagement during therapy for PTSD in the correct circumstances. Future systems should consider expanding these interfaces in an appropriate manner for clinicians and veterans not served in this work.

# Appendices

## Qualitative Code Book

*Study 3: Using Sensor-Captured Patient-Generated Data to Support Clinician Intuition and Patient Self-Report in PTSD Therapy Code Book*

| **Parent Code** | **Child Code(s) (if any)** | **Description** | **Example** |
|---|---|---|---|
| Barriers to Clinician Use of PEQ | Anything that might stop a clinician from using the system from the clinician's perspective | | *Is [going over PEQ data] something that is going to take 2 minutes or is it taking 30 minutes and pulling us away from the point of the session?* |
| Barriers to Veteran Use of PEQ | Anything that might stop a veteran from using the system from the clinician's perspective | | *There are going to be some patients who don't want us to record the sessions – it is probably coming from a place of discomfort and avoidance – they won't want their therapist 'monitoring' them.* |
| Clinical-Decision Making | The action or process of making decisions regarding patient care by a clinician. This can be anything from the direction of a conversation or question to ask to a change in therapy at large. This can refer to their current practice or imagined decision-making using PEQ. | | *I might be inclined to, you know, talk with the patient about the context in which they're doing their homework and figure out with them how it might be improved to set them up for more benefit from doing homework.* |
| Clinician and Patient Relationship | Describes characteristics of the clinician and patient relationship. Refers to the way that patients and clinicians behave towards each other. | | *I usually try to build rapport with someone where they can be open with me.* |
| | How to Address PEQ Data | Describes the manner in which a clinician would approach PEQ data (e.g. would they ask a question, give feedback, etc.) | *I wouldn't address the PEQ data specifically. I would ask about the homework like I usually do and then let the patient bring up any data they think is relevant.* |
| | Tailoring Treatment / Deviation from the Norm | Refers to any time a clinician tailors treatment to meet patient needs; may refer to 'bending' the protocol to do things they might not normally do such as allowing a patient to reenact memories or move. | *I bend the protocol to meet the patient's needs.* |

| | | | |
|---|---|---|---|
| | When to Address PEQ Data | Describes when in the overall therapy OR when in the session the clinician would address PEQ data with patients | *I would address the PEQ data in the first couple of sessions only. That way, I could help the patient address problematic behavior that is distracting them but I wouldn't use it in every session.* |
| Clinician Intuition | Clinicians utilize their intuition to navigate and extrapolate from veteran's self-report. Clinicians explain that during therapy sessions, they probe veterans' experiences more deeply to better understand how veterans cope and manage their lives. | | |
| Clinician Knowledge of World Outside of Office Setting | When the clinician shares understanding of outside world of the patient as part of their care practice. | | *I know about my patient's home life, especially with telehealth in the pandemic. I know about noises and people in the house.* |
| Data Access | Describes which data and when clinicians would grant patients access to PEQ data | | *I would give them access immediately.* |
| Data Privacy | Concern by both veterans and clinicians regarding patient data in technology systems | | *Veterans might be concerned about what is being recorded and stored through PEQ.* |
| Impressions - Utility and Usability | Anything that refers to a clinician's perception of the utility, functionality, or usability of any portion of the PEQ system. | | *I'm not sure how much utility this would actually have in a session.* |
| | It Gives Me a Little Extra | Refers to clinicians explaining how PEQ data builds upon what they already gather as part of their imaginal exposure therapy exercise guidance and evaluation process. PEQ provides supplemental data. | *PE works without PEQ but the information is interesting. I could use it to help the patient early on in treatment with things they might not mention.* |
| Interpreting PEQ Data | How a clinician interprets PEQ data on the interface. | | *I think the average of the PEQ is easy to read.* |
| | Combining Sensors | How a clinician combines different data streams to interpret PEQ data on the interface | *I would look to see if heart rate correlated with their physical movement.* |
| | Heart Rate | How a clinician interprets heart rate PEQ data on the interface | *I think the heart rate spikes look similar from the clinician guided imaginal to the patient imaginal for homework.* |
| | Noise Levels | How a clinician interprets noise level PEQ data on the interface | *I'm not sure I understand what noise level even means.* |

| | | | |
|---|---|---|---|
| | Phone Usage | Clinician perception and understanding of phone usage data displayed in PEQ interface | *I am concerned the patient used their phone this much during their imaginal.* |
| | Physical Activity | How a clinician interprets physical activity PEQ data on the interface | *I can see that the patient got up and walked during homework.* |
| | What’s Missing | Refers to what clinicians describe as "missing" or what they desire to have that is not currently captured in the PEQ data streams or interface. | *I wish we could see GSR here instead of heart rate.* |
| Seeing Progress/Habituation/ Over Time | Demonstrating treatment progress is both motivational and informative for veterans. This can be prompted by clinicians or veterans and seen by both parties. There can be progress or lack of progress from session to homework or between sessions. | | *I have patients chart their SUDs so they can see a visual of their progress over sessions.* |
| Self-Report | Refers to any mention or method of self-report. Self-report is limited as it is inherently biased; this can be especially difficult for veterans with TBI. They may use strategies to improve recall (e.g., use mobile apps, notebook, or worksheets) | | *Patients use worksheets to write down their SUDs from the imaginal homework.* |
| | Self-report quality | Refers to clinician perception of patients' self-report quality | *Usually patients don’t lie and it’s pretty easy to tell if they are lying.* |
| | SUDs Calibration | Discusses the process of clinicians helping veterans establish SUDS anchor points | *I help a patient think of the most distressed they’ve ever been to set the high anchor point.* |
| Understanding of System Functionality | Describes how clinicians believe the backend functionality of the PEQ system to work; does not describe specific visual aspects of the interface by themselves. Must describe perceived functionality behind the design. | | *Does the noise level record the audio from the recorded imaginal?* |
| Use of Technology | Any technology used to collect and store data for veteran mental health care by any party involved in the network of care. | | *I use a Discord Server to store and send documents to veterans.* |

# References

1. Saeed Abdullah, Elizabeth L Murnane, Mark Matthews, Matthew Kay, Julie A Kientz, Geri Gay, and Tanzeem Choudhury. 2016. Cognitive Rhythms: Unobtrusive and Continuous Sensing of Alertness Using a Mobile Phone. In *Proceedings of the 2016 ACM International Joint Conference on Pervasive and Ubiquitous Computing* (UbiComp '16), 178–189. https://doi.org/10.1145/2971648.2971712
2. Jonathan S Abramowitz, Brett J Deacon, and P H Whiteside Stephen. 2019. *Exposure Therapy for Anxiety, Second Edition: Principles and Practice*. Guildford Press.
3. Thomas M Achenbach, Paul A Newhouse, and Leslie Rescorla. 2004. *Manual for the ASEBA older adult forms & profiles*. ASEBA.
4. Wolfgang Aigner, Silvia Miksch, H Schumann, and Christian Tominski. 2011. *Visualization of Time-Oriented Data*. https://doi.org/10.1007/978-0-85729-079-3
5. American Psychiatric Association. 2013. *Diagnostic and statistical manual of mental disorders (5th Ed).* American Psychiatric Association.
6. Patricia Areán and Pim Cuijpers. 2017. Technology and mental health. *Depression and Anxiety* 34, 6. https://doi.org/10.1002/da.22636
7. Rosa I. Arriaga. 2016. Chapter 20 Using an ecological systems approach to target technology development for autism research and beyond. In *Autism Imaging and Devices*. CRC Press, 419–436. https://doi.org/10.1201/9781315371375-21
8. Assistant Secretary for Public Affairs. 2013. System Usability Scale (SUS). *Usability.gov*. Retrieved from https://www.usability.gov/how-to-and-tools/methods/system-usability-scale.html
9. Boniel-Nissim M & Suler J Barak A. 2008. Fostering Empowerment in Online Support Groups. *Computers in Human Behavior* 24, 5: 1867–1883.
10. Jakob E Bardram, Mads Frost, Károly Szántó, Maria Faurholt-Jepsen, Maj Vinberg, and Lars Vedel Kessing. 2013. Designing Mobile Health Technology for Bipolar Disorder: A Field Trial of the Monarca System. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. Association for Computing Machinery, New York, NY, USA, 2627–2636. Retrieved from https://doi.org/10.1145/2470654.2481364
11. Greg Barish, Hilary Aralis, Eric Elbogen, and Patricia Lester. 2019. A Mobile App for Patients and Those Who Care About Them: A Case Study for Veterans with PTSD + Anger. In *Proceedings of the 13th EAI International Conference on Pervasive Computing Technologies for Healthcare* (PervasiveHealth'19), 1–10. https://doi.org/10.1145/3329189.3329248
12. V Barr, Sylvia Robinson, Brenda Marin-Link, Lisa Underhill, Anita Dotts, Darlene Ravensdale, and Sandy Salivaras. 2003. The expanded chronic care model. *Hosp Q* 7, 1: 73–82.
13. Roni Berger and Tzipi Weiss. 2009. The posttraumatic growth model: An expansion to the family system. *Traumatology* 15, 1: 63–74.
14. Ana M Bernardos, Marcos Pires, Daniel Ollé, and José R Casar. 2019. Digital Phenotyping as a Tool for Personalized Mental Healthcare. In *Proceedings of the 13th EAI International Conference on Pervasive Computing Technologies for Healthcare* (PervasiveHealth'19), 403–408. https://doi.org/10.1145/3329189.3329240
15. Andrew B L Berry, Catherine Lim, Andrea L Hartzler, Tad Hirsch, Edward H Wagner, Evette Ludman, and James D Ralston. 2017. How Values Shape Collaboration Between

Patients with Multiple Chronic Conditions and Spousal Caregivers. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (CHI '17), 5257–5270. https://doi.org/10.1145/3025453.3025923

16. D Biddle, P Elliott, M Creamer, D Forbes, and G J Devilly. 2002. Self-reported problems: a comparison between PTSD-diagnosed veterans, their spouses, and clinicians. *Behaviour Research and Therapy* 40, 7: 853–865. https://doi.org/10.1016/S0005-7967(01)00084-5
17. Renato Bispo -PhD Student. 2008. *Designing out stigma-The role of objects in the construction of disabled people´s identity*.
18. Jonathan I Bisson, Neil P Roberts, Martin Andrew, Rosalind Cooper, and Catrin Lewis. 2013. Psychological therapies for chronic post-traumatic stress disorder (PTSD) in adults. *Cochrane Database of Systematic Reviews*.
19. Christy A Blevins, Frank W Weathers, Margaret T Davis, Tracy K Witte, and Jessica L Domino. 2015. The Posttraumatic Stress Disorder Checklist for *DSM-5* (PCL-5): Development and Initial Psychometric Evaluation. *Journal of Traumatic Stress* 28, 6. https://doi.org/10.1002/jts.22059
20. C S Bond, Mark Merolli, and O H Ahmed. 2016. Patient empowerment through social media. In *Participatory health through social media*. Elsevier, 10–26.
21. Cristina Botella, Azucena Garcia-Palacios, Veronica Guillen, Rosa Maria Baños, Soledad Quero, and Mariano Alcaniz. 2010. An Adaptive Display for the Treatment of Diverse Trauma PTSD Victims. *Cyberpsychology, Behavior, and Social Networking*. https://doi.org/10.1089/cyber.2009.0353
22. Cristina Botella, Azucena García-Palacios, Veronica Guillen, Rosa Maria Baños, Soledad Quero, and Mariano Alcaniz. 2010. An Adaptive Display for the Treatment of Diverse Trauma PTSD Victims. *Cyberpsychology, Behavior, and Social Networking*. https://doi.org/10.1089/cyber.2009.0353
23. Cristina Botella, Berenice Serrano, Rosa M Baños, and Azucena Garcia-Palacios. 2015. Virtual reality exposure-based therapy for the treatment of post-traumatic stress disorder: A review of its efficacy, the adequacy of the treatment protocol, and its acceptability. *Neuropsychiatric Disease and Treatment*. https://doi.org/10.2147/NDT.S89542
24. Cristina Botella, Berenice Serrano, Rosa M Baños, and Azucena Garcia-Palacios. 2015. Virtual reality exposure-based therapy for the treatment of post-traumatic stress disorder: A review of its efficacy, the adequacy of the treatment protocol, and its acceptability. *Neuropsychiatric Disease and Treatment*. https://doi.org/10.2147/NDT.S89542
25. Scott R Braithwaite, Christophe Giraud-Carrier, Josh West, Michael D Barnes, and Carl Lee Hanson. 2016. Validating Machine Learning Algorithms for Twitter Data Against Established Measures of Suicidality. *JMIR Mental Health* 3, 2. https://doi.org/10.2196/mental.4822
26. V Braun and V Clarke. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 2: 77–101. https://doi.org/10.1191/1478088706qp063oa
27. Deborah J. Brief, Amy Rubin, Terence M. Keane, Justin L. Enggasser, Monica Roy, Eric Helmuth, John Hermos, Mark Lachowicz, Denis Rybin, and David Rosenbloom. 2013. Web intervention for OEF/OIF veterans with problem drinking and PTSD symptoms: A randomized clinical trial. *Journal of Consulting and Clinical Psychology* 81, 5: 890–900. https://doi.org/10.1037/a0033697
28. U Bronfenbrenner. 1979. The Ecology of Human Development. *Harvard University Press*.

29. Alice v Brown and Jaz Hee-jeong Choi. 2017. Towards Care-based Design. In *Proceedings of the 8th International Conference on Communities and Technologies*. https://doi.org/10.1145/3083671.3083703
30. Lawrence G Calhoun and R G Tedeschi. 1995. Trauma and transformation: Growing in the aftermath of suffering.
31. Yunan Chen, Victor Ngo, and Sun Young Park. 2013. Caring for caregivers. In *Proceedings of the 2013 conference on Computer supported cooperative work - CSCW '13*, 91. https://doi.org/10.1145/2441776.2441789
32. Isabel Chien, Angel Enrique, Jorge Palacios, Tim Regan, Dessie Keegan, David Carter, Sebastian Tschiatschek, Aditya Nori, Anja Thieme, Derek Richards, Gavin Doherty, and Danielle Belgrave. 2020. A Machine Learning Approach to Understanding Patterns of Engagement with Internet-Delivered Mental Health Interventions. *JAMA Network Open* 3, 7: 2010791. https://doi.org/10.1001/jamanetworkopen.2020.10791
33. Matthew Chinman, Preethy George, Richard H Dougherty, Allen S Daniels, Sushmita Shoma Ghose, Anita Swift, and Miriam E Delphin-Rittmon. 2014. Peer Support Services for Individuals With Serious Mental Illnesses: Assessing the Evidence. *Psychiatric Services* 65, 4: 429–441. https://doi.org/10.1176/appi.ps.201300244
34. William J Chopik. 2016. The Benefits of Social Technology Use Among Older Adults Are Mediated by Reduced Loneliness. *Cyberpsychology, Behavior, and Social Networking* 19, 9: 551–556. https://doi.org/10.1089/cyber.2016.0151
35. Chia Fang Chung, Jonathan Cook, Elizabeth Bales, Jasmine Zia, and Sean A. Munson. 2015. More than telemonitoring: Health provider use and nonuse of life-log data in irritable bowel syndrome and weight management. *Journal of Medical Internet Research* 17, 8. https://doi.org/10.2196/jmir.4364
36. Joshua D Clapp and J Gayle Beck. 2009. Understanding the relationship between PTSD and social support: The role of negative network orientation. *Behaviour research and therapy* 47, 3: 237–244.
37. Jane Clemensen, J Rasmussen, A Denning, and M Craggs. 2011. Patient empowerment and new citizen roles through telehealth technologies. In *Proceedings of conference eTELEMED*, 23–28.
38. Beth E Cohen, Kris Gima, Daniel Bertenthal, Sue Kim, Charles R Marmar, and Karen H Seal. 2009. Mental Health Diagnoses and Utilization of VA Non-Mental Health Medical Services Among Returning Iraq and Afghanistan Veterans. *Journal of General Internal Medicine* 25: 18–24.
39. Jose E Coll, Eugenia L Weiss, and Jeffrey S Yarvis. 2011. No One Leaves Unchanged: Insights for Civilian Mental Health Care Professionals Into the Military Experience and Culture. *Social Work in Health Care* 50, 7: 487–500. https://doi.org/10.1080/00981389.2010.528727
40. Joseph J Collins. 1998. The complex context of American military culture: A practitioner's view. *The Washington Quarterly* 21, 4: 213–228. https://doi.org/10.1080/01636609809550359
41. Patrick W Corrigan, Benjamin G Druss, and Deborah A Perlick. 2014. The impact of mental illness stigma on seeking and participating in mental health care. *Psychological Science in the Public Interest, Supplement*. https://doi.org/10.1177/1529100614531398

42. Patrick W Corrigan and Jenessa R Shapiro. 2010. Measuring the impact of programs that challenge the public stigma of mental illness. *Clinical Psychology Review*. https://doi.org/10.1016/j.cpr.2010.06.004
43. Patrick W Corrigan and Amy C Watson. 2002. The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice* 9, 1: 35–53.
44. Karen Cusack, Daniel E Jonas, Catherine A Forneris, Candi Wines, Jeffrey Sonis, Jennifer Cook Middleton, Cynthia Feltner, Kimberly A Brownley, Kristine Rae Olmsted, Amy Greenblatt, Amy Weil, and Bradley N Gaynes. 2016. Psychological treatments for adults with posttraumatic stress disorder: A systematic review and meta-analysis. *Clinical Psychology Review* 43: 128–141.
45. Jenny L Davis. 2020. *How artifacts afford: The power and politics of everyday things*. MIT Press.
46. Jenny L Davis. 2020. *How artifacts afford: The power and politics of everyday things*. MIT Press.
47. Bryann B DeBeer, Nathan A Kimbrel, Eric C Meyer, Suzy B Gulliver, and Sandra B Morissette. 2014. Combined PTSD and depressive symptoms interact with post-deployment social support to predict suicidal ideation in Operation Enduring Freedom and Operation Iraqi Freedom veterans. *Psychiatry Research* 216, 3. https://doi.org/10.1016/j.psychres.2014.02.010
48. Wenrui Deng, Die Hu, S. Xu, Xiaoyu Liu, Jingwen Zhao, Qian Chen, Jiayuan Liu, Z. Zhang, Wenxiu Jiang, L. Ma, X. Hong, Shengrong Cheng, Boya Liu, and Xiaoming Li. 2019. The efficacy of virtual reality exposure therapy for PTSD symptoms: A systematic review and meta-analysis. *Journal of Affective Disorders 257*, 698–709. https://doi.org/10.1016/j.jad.2019.07.086
49. Bryan Dosono, Yasmeen Rashidi, Taslima Akter, Bryan Semaan, and Apu Kapadia. 2017. Challenges in transitioning from civil to military culture: Hyper-selective disclosure through ICTs. *Proceedings of the ACM on Human-Computer Interaction* 1, CSCW: 41.
50. Louise A Ellis, Philippa Collin, Patrick J Hurley, Tracey A Davenport, Jane M Burns, and Ian B Hickie. 2013. Young men's attitudes and behaviour in relation to mental health and technology: implications for the development of online mental health services. *BMC psychiatry* 13, 1: 119.
51. Hayley Evans, Udaya Lakshmi, Hue Watson, Azra Ismail, Andrew M Sherrill, Neha Kumar, and Rosa I Arriaga. 2020. Understanding the Care Ecologies of Veterans with PTSD. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. Association for Computing Machinery, New York, NY, USA, 1–15. Retrieved from https://doi.org/10.1145/3313831.3376170
52. Karin M. Eyrich-Garg. 2010. Mobile phone technology: A new paradigm for the prevention, treatment, and research of the non-sheltered "street" homeless? *Journal of Urban Health* 87, 3: 365–380. https://doi.org/10.1007/s11524-010-9456-2
53. Charles R Figley. 2002. *Treating compassion fatigue*. Routledge.
54. Brooke A Fina, Edward C Wright, Sheila A M Rauch, Sonya B Norman, Ron Acierno, Lisa-Ann J Cuccurullo, Katherine A Dondanville, John C Moring, Lily A Brown, and Edna B Foa. 2020. Conducting Prolonged Exposure for PTSD During the COVID-19 Pandemic: Considerations for Treatment. *Cognitive and Behavioral Practice*. https://doi.org/10.1016/j.cbpra.2020.09.003

55. Deborah L Finfgeld. 2004. Empowerment of individuals with enduring mental health problems: Results from concept analyses and qualitative investigations. *Advances in Nursing Science* 27, 1: 44–52.
56. Geraldine Fitzpatrick and Gunnar Ellingsen. 2013. A review of 25 years of CSCW research in healthcare: contributions, challenges and future agendas. *Computer Supported Cooperative Work (CSCW)* 22, 4–6: 609–665.
57. Edna B Foa, Elizabeth Ann Hembree, and Barbara Olasov Rothbaum. 2007. *Prolonged exposure therapy for PTSD : emotional processing of traumatic experiences : therapist guide*. Oxford University Press.
58. Edna Foa, Elizabeth A Hembree, Barbara Olasov Rothbaum, and Sheila Rauch. 2019. *Prolonged Exposure Therapy for PTSD*. Oxford University Press. https://doi.org/10.1093/med-psych/9780190926939.001.0001
59. Edna Foa, Elizabeth A Hembree, Barbara Olasov Rothbaum, and Sheila Rauch. 2019. *Prolonged Exposure Therapy for PTSD*. Oxford University Press. https://doi.org/10.1093/med-psych/9780190926939.001.0001
60. Pin Sym Foong, Shengdong Zhao, Felicia Tan, and Joseph Jay Williams. 2018. Harvesting Caregiving Knowledge. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems - CHI '18*, 1–12. https://doi.org/10.1145/3173574.3173653
61. Center for Substance Abuse Treatment (US). 2014. DSM-5 Diagnostic Criteria for PTSD. *TIP 57: Trauma-Informed Care in Behavioral Health Services 57*.
62. New Directions for Veterans. Common Issues Facing Veterans. *Common Issues Facing Veterans*. Retrieved from https://ndvets.org/programs-services/mental-health/common-issues-facing-veterans/
63. S. L. Foster and J. D. Cone. 1995. Validity issues in clinical assessment. *Psychological Assessment 7*, 248–260. https://doi.org/10.1037/1040-3590.7.3.248
64. Charles Froland, Gerry Brodsky, Madeline Olson, and Linda Stewart. 2000. Social Support and Social Adjustment: Implications for Mental Health Professionals. *Community Mental Health Journal* 36, 1. https://doi.org/10.1023/A:1001804727462
65. Mads Frost, Afsaneh Doryab, Maria Faurholt-Jepsen, Lars Kessing, and Jakob E. Bardram. 2013. Supporting disease insight through data analysis: Refinements of the MONARCA self-assessment system. In *UbiComp 2013 - Proceedings of the 2013 ACM International Joint Conference on Pervasive and Ubiquitous Computing*, 133–142. https://doi.org/10.1145/2493432.2493507
66. James G Gallagher, David S Riggs, Christina A Byrne, and Frank W Weathers. 1998. Female partners' estimations of male veterans' combat-related PTSD severity. *Journal of Traumatic Stress* 11, 2: 367–374. https://doi.org/10.1023/A:1024411422586
67. Hector A Garcia, Erin P Finley, Norma Ketchum, Matthew Jakupcak, Albana Dassori, and Stephanie C Reyes. 2014. A Survey of Perceived Barriers and Attitudes Toward Mental Health Care Among OEF/OIF Veterans at VA Outpatient Mental Health Clinics. *Military Medicine* 179, 3: 273–278. https://doi.org/10.7205/MILMED-D-13-00076
68. Elizabeth M Goetter, Eric Bui, Rebecca A Ojserkis, Rebecca J Zakarian, Rebecca Weintraub Brendel, and Naomi M Simon. 2015. A Systematic Review of Dropout From Psychotherapy for Posttraumatic Stress Disorder Among Iraq and Afghanistan Combat Veterans. *Journal of Traumatic Stress* 28, 5. https://doi.org/10.1002/jts.22038
69. Erving Goffman. 1963. Stigma: notes on the management of spoiled identity.

70. Erving Goffman. *Stigma : notes on the management of spoiled identity*. Retrieved January 15, 2018 from http://www.simonandschuster.com/books/Stigma/Erving-Goffman/9780671622442
71. Raquel Gonçalves, Ana Lúcia Pedrozo, Evandro Silva Freire Coutinho, Ivan Figueira, and Paula Ventura. 2012. Efficacy of Virtual Reality Exposure Therapy in the Treatment of PTSD: A Systematic Review. *PLoS ONE 7*, 48469. https://doi.org/10.1371/journal.pone.0048469
72. Guendalina Graffigna, Serena Barello, Andrea Bonanomi, and Edoardo Lozza. 2015. Measuring patient engagement: development and psychometric properties of the Patient Health Engagement (PHE) Scale. *Frontiers in Psychology* 6, MAR: 274. https://doi.org/10.3389/fpsyg.2015.00274
73. Guendalina Graffigna, Serena Barello, and Stefano Triberti. 2016. *Patient engagement: A consumer-centered model to innovate healthcare*. Walter de Gruyter GmbH &amp; Co KG.
74. John F Greden, Marcia Valenstein, Jane Spinner, Adrian Blow, Lisa A Gorman, Gregory W Dalack, Sheila Marcus, and Michelle Kees. 2010. Buddy-to-Buddy, a citizen soldier peer support program to counteract stigma, PTSD, depression, and suicide. *Annals of the New York Academy of Sciences*. https://doi.org/10.1111/j.1749-6632.2010.05719.x
75. Daniel F. Gros, Leslie A. Morland, Carolyn J. Greene, Ron Acierno, Martha Strachan, Leonard E. Egede, Peter W. Tuerk, Hugh Myrick, and B. Christopher Frueh. 2013. Delivery of evidence-based psychotherapy via video telehealth. *Journal of Psychopathology and Behavioral Assessment* 35, 4: 506–521. https://doi.org/10.1007/s10862-013-9363-4
76. Daniel F Gros, Matthew Price, Erica K Yuen, and Ron Acierno. 2013. PREDICTORS OF COMPLETION OF EXPOSURE THERAPY IN OEF/OIF VETERANS WITH POSTTRAUMATIC STRESS DISORDER. *Depression and Anxiety* 30, 11: 1107–1113. https://doi.org/https://doi.org/10.1002/da.22207
77. Francisco J Gutierrez and Sergio F Ochoa. 2017. It Takes at Least Two to Tango: Understanding the Cooperative Nature of Elderly Caregiving in Latin America. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing* (CSCW '17), 1618–1630. https://doi.org/10.1145/2998181.2998314
78. Lynn Hall. 2011. The Importance of Understanding Military Culture. *Social Work in Health Care* 50, 1: 4–18. https://doi.org/10.1080/00981389.2010.513914
79. Donna Haraway. 1988. Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective. *Feminist Studies* 14, 3: 575. https://doi.org/10.2307/3178066
80. Donna Haraway. 2006. A cyborg manifesto: Science, technology, and socialist-feminism in the late 20th century. In *The international handbook of virtual learning environments*. Springer, 117–158.
81. Rachel L. Harrington, Maya L. Hanna, Elisabeth M. Oehrlein, Rob Camp, Russell Wheeler, Clarissa Cooblall, Theresa Tesoro, Amie M. Scott, Rainald von Gizycki, Francis Nguyen, Asha Hareendran, Donald L. Patrick, and Eleanor M. Perfetto. 2020. Defining Patient Engagement in Research: Results of a Systematic Review and Analysis: Report of the ISPOR Patient-Centered Special Interest Group. *Value in Health* 23, 6: 677–688. https://doi.org/10.1016/j.jval.2020.01.019

82. Allison G Harvey, Richard A Bryant, and Nicholas Tarrier. 2003. Cognitive behaviour therapy for posttraumatic stress disorder. *Clinical Psychology Review* 23: 501–522.
83. Sara and Thornicroft Graham Henderson Claire and Evans-Lacko. 2013. Mental illness stigma, help seeking, and public health programs. *Am J Public Health* 103, 5: 777–780. https://doi.org/10.2105/AJPH.2012.301056
84. Tracy Higgins, Elaine Larson, and Rebecca Schnall. 2017. Unraveling the meaning of patient engagement: A concept analysis. *Patient Education and Counseling* 100, 1: 30–36. https://doi.org/10.1016/j.pec.2016.09.002
85. Terra C Holdeman. 2009. Invisible wounds of war: Psychological and cognitive injuries, their consequences, and services to assist recovery. *Psychiatric Services* 60, 2: 273.
86. Yarosh S Kim J Abowd G Arriaga R Hong H. 2018. Investigating the use of circles in social networks to support independence of individuals with autism. *Proc. ACM Hum.-Comput. Interact.*, CHI. https://doi.org/10.1145/2470654.2466439
87. Matthew K Hong, Lauren Wilcox, Daniel Machado, Thomas A Olson, and Stephen F Simoneaux. 2016. Care Partnerships: Toward Technology to Support Teens' Participation in Their Health Care. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems* (CHI '16), 5337–5349. https://doi.org/10.1145/2858036.2858508
88. Kathryn L Humphreys, Carl F Weems, and Michael S Scheeringa. 2017. The role of anxiety control and treatment implications of informant agreement on child PTSD symptoms. *Journal of Clinical Child & Adolescent Psychology* 46, 6: 903–914.
89. John Hunsley and Eric J. Mash. Evidence-Based Assessment. Retrieved October 22, 2021 from https://papers.ssrn.com/abstract=1051821
90. Zac E Imel, Kevin Laska, Matthew Jakupcak, and Tracy L Simpson. 2013. Meta-analysis of dropout in treatments for posttraumatic stress disorder. *Journal of Consulting and Clinical Psychology* 81, 3. https://doi.org/10.1037/a0031474
91. Washington University in St. Louis. 2008. Growing Problem For Veterans: Domestic Violence. *ScienceDaily*. Retrieved from https://www.sciencedaily.com/releases/2008/11/081106181415.htm
92. Azra Ismail, Naveena Karusala, and Neha Kumar. 2018. Bridging Disconnected Knowledges for Community Health. *Proc. ACM Hum.-Comput. Interact.* 2, CSCW. https://doi.org/10.1145/3274344
93. Azra Ismail, Naveena Karusala, and Neha Kumar. 2018. Bridging Disconnected Knowledges for Community Health. *Proc. ACM Hum.-Comput. Interact.* 2, CSCW. https://doi.org/10.1145/3274344
94. Riitta Jääskeläinen. 2010. Think-aloud protocol. . 371–373. https://doi.org/10.1075/hts.1.thi1
95. Maia L Jacobs, James Clawson, and Elizabeth D Mynatt. 2015. Comparing Health Information Sharing Preferences of Cancer Patients, Doctors, and Navigators. In (CSCW '15), 808–818. https://doi.org/10.1145/2675133.2675252
96. Hee Young Jeong and Rosa I Arriaga. 2009. Using an ecological framework to design mobile technologies for pediatric asthma management. In *Proceedings of the 11th International Conference on Human-Computer Interaction with Mobile Devices and Services - MobileHCI '09*.
97. Alan E. Kazdin. 2017. Addressing the treatment gap: A key challenge for extending evidence-based psychosocial interventions. *Behaviour Research and Therapy 88*, 7–18. https://doi.org/10.1016/j.brat.2016.06.004

98. Elizabeth Kaziunas, Mark S Ackerman, Silvia Lindtner, and Joyce M Lee. 2017. Caring Through Data: Attending to the Social and Emotional Experiences of Health Datafication. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing* (CSCW '17), 2260–2272. https://doi.org/10.1145/2998181.2998303
99. Saskia Marion Kelders, Hanneke Kip, and Japie Greeff. 2020. Psychometric evaluation of the Twente Engagement with Ehealth Technologies Scale (TWEETS): Evaluation study. *Journal of Medical Internet Research* 22, 10: e17757. https://doi.org/10.2196/17757
100. Christina Kelley, Bongshin Lee, and Lauren Wilcox. 2017. Self-tracking for mental wellness: Understanding expert perspectives and student experiences. In *Conference on Human Factors in Computing Systems - Proceedings*, 629–641. https://doi.org/10.1145/3025453.3025750
101. Ronald C Kessler, Wai Tat Chiu, Olga Demler, and Ellen E Walters. 2005. Prevalence, severity, and comorbidity of 12-month DSM-IV disorders in the National Comorbidity Survey Replication. *Archives of general psychiatry* 62, 6: 617–627.
102. Mohammed Khwaja, Svenja Pieritz, A. Aldo Faisal, and Aleksandar Matic. 2021. Personality and engagement with digital mental health interventions. In *UMAP 2021 - Proceedings of the 29th ACM Conference on User Modeling, Adaptation and Personalization*, 235–239. https://doi.org/10.1145/3450613.3456823
103. Julie Kientz, Gillian Hayes, Tracy Westeyn, Thad Starner, and Gregory Abowd. 2007. Pervasive Computing and Autism: Assisting Caregivers of Children with Special Needs. *IEEE Pervasive Computing* 6, 1: 28–35. https://doi.org/10.1109/MPRV.2007.18
104. Christopher J Koenig, Shira Maguen, Jose D Monroy, Lindsay Mayott, and Karen H Seal. 2014. Facilitating culture-centered communication between health care providers and veterans transitioning from military deployment to civilian life. *Patient Education and Counseling* 95, 3: 414–420. https://doi.org/10.1016/J.PEC.2014.03.016
105. Annika Kuester, Helen Niemeyer, and Christine Knaevelsrud. 2016. Internet-based interventions for posttraumatic stress: A meta-analysis of randomized controlled trials. *Clinical Psychology Review 43*, 1–16. https://doi.org/10.1016/j.cpr.2015.11.004
106. Eric Kuhn, Jill J Crowley, Julia E Hoffman, Afsoon Eftekhari, Kelly M Ramsey, Jason E Owen, Greg M Reger, and Josef I Ruzek. 2015. Clinician characteristics and perceptions related to use of the PE (prolonged exposure) coach mobile app. *Professional Psychology: Research and Practice* 46: 437–443.
107. Eric Kuhn, Nitya Kanuri, Julia E. Hoffman, Donn W. Garvert, Josef I. Ruzek, and C. Barr Taylor. 2017. A randomized controlled trial of a smartphone app for posttraumatic stress disorder symptoms. *Journal of Consulting and Clinical Psychology* 85, 3: 267–273. https://doi.org/10.1037/ccp0000163
108. Antonio Lanatà, Gaetano Valenza, Mimma Nardelli, Claudio Gentili, and Enzo Scilingo. 2014. Complexity Index From a Personalized Wearable Monitoring System for Assessing Remission in Mental Health. *IEEE journal of biomedical and health informatics* 19. https://doi.org/10.1109/JBHI.2014.2360711
109. Brian M. Landry, Eun Kyoung Choe, Stephen McCutcheon, and Julie A. Kientz. 2010. Post-traumatic stress disorder. In *Proceedings of the ACM international conference on Health informatics - IHI '10*, 780. https://doi.org/10.1145/1882992.1883110

110. Richard Laugharne and Stefan Priebe. 2006. Trust, choice and power in mental health: A literature review. *Social Psychiatry and Psychiatric Epidemiology* 41, 11: 843–852. https://doi.org/10.1007/s00127-006-0123-6

111. Daniel J. Lee, Sarah E. Kleiman, and Frank W. Weathers. 2019. Assessment of Trauma- and Stressor-Related Disorders. In *The Cambridge Handbook of Clinical Assessment and Diagnosis*. Cambridge University Press, 347–359. https://doi.org/10.1017/9781108235433.025

112. Hyo-Il Lee Jung-Hyun and Jung. 2013. Biochip technology for monitoring posttraumatic stress disorder (PTSD). *BioChip Journal* 7, 3: 195–200. https://doi.org/10.1007/s13206-013-7301-x

113. Cara C. Lewis, Meredith Boyd, Ajeng Puspitasari, Elena Navarro, Jacqueline Howard, Hannah Kassab, Mira Hoffman, Kelli Scott, Aaron Lyon, Susan Douglas, Greg Simon, and Kurt Kroenke. 2019. Implementing Measurement-Based Care in Behavioral Health: A Review. *JAMA Psychiatry* 76, 3: 324–335. https://doi.org/10.1001/jamapsychiatry.2018.3329

114. James R. Lewis. 2002. Psychometric Evaluation of the PSSUQ Using Data from Five Years of Usability Studies. *International Journal of Human-Computer Interaction* 14, 3–4: 463–488. https://doi.org/10.1080/10447318.2002.9669130

115. James R. Lewis. 2018. Measuring Perceived Usability: The CSUQ, SUS, and UMUX. *International Journal of Human-Computer Interaction* 34, 12: 1148–1156. https://doi.org/10.1080/10447318.2017.1418805

116. Heather Littleton, Amie E. Grills, Katherine D. Kline, Alexander M. Schoemann, and Julia C. Dodd. 2016. The From Survivor to Thriver program: RCT of an online therapist-facilitated program for rape-related PTSD. *Journal of Anxiety Disorders* 43: 41–51. https://doi.org/10.1016/j.janxdis.2016.07.010

117. Leslie S Liu, Sen H Hirano, Monica Tentori, Karen G Cheng, Sheba George, Sun Young Park, and Gillian R Hayes. 2011. Improving communication and social support for caregivers of high-risk infants through mobile technologies. In *Proceedings of the ACM 2011 conference on Computer supported cooperative work*, 475–484.

118. Nicholas A Livingston, Daniel J Lee, Colin T Mahoney, Stacey L Farmer, Travis Cole, Brian P Marx, and Terence M Keane. 2021. Longitudinal assessment of PTSD and illicit drug use among male and female OEF-OIF veterans. *Addictive Behaviors* 118. https://doi.org/10.1016/j.addbeh.2021.106870

119. Juan F Maestre, Jessica Pater, Georgia Tech, Elizabeth v Eikey, Maia Jacobs, Mark Warner, Gabriela Marcu, Svetlana Yarosh, and Patrick C Shih. 2018. Conducting Research with Stigmatized Populations: Practices, Challenges, and Lessons Learned. https://doi.org/10.1145/3272973.3273003

120. Lena Mamykina, Elizabeth D Mynatt, and David R Kaufman. 2006. Investigating health management practices of individuals with diabetes. In *Proceedings of the SIGCHI conference on Human Factors in computing systems*, 927–936.

121. Lena Mamykina, Elizabeth Mynatt, Patricia Davidson, and Daniel Greenblatt. 2008. MAHI: Investigation of Social Scaffolding for Reflective Thinking in Diabetes Management. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (CHI ’08), 477–486. https://doi.org/10.1145/1357054.1357131

122. Lena Mamykina, Elizabeth Mynatt, Patricia Davidson, and Daniel Greenblatt. 2008. MAHI: investigation of social scaffolding for reflective thinking in diabetes management.

In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 477–486.

123. Gabriela Marcu, Nadia Dowshen, Shuvadittya Saha, Ressa Sarreal, and Nazanin Andalibi. 2016. TreatYoSelf: Empathy-driven behavioral intervention for marginalized youth living with HIV. In *Proceedings of the 10th EAI International Conference on Pervasive Computing Technologies for Healthcare*. https://doi.org/10.4108/eai.16-5-2016.2263336
124. Alison Mathie and Gord Cunningham. 2005. Who is driving development? Reflections on the transformative potential of asset-based community development. *Canadian Journal of Development Studies/Revue canadienne d'études du développement* 26, 1: 175–186.
125. Mark Matthews, Saeed Abdullah, Elizabeth Murnane, Stephen Voida, Tanzeem Choudhury, Geri Gay, and Ellen Frank. 2016. Development and Evaluation of a Smartphone-Based Measure of Social Rhythms for Bipolar Disorder. *Assessment* 23, 4: 472–483. https://doi.org/10.1177/1073191116656794
126. Mark Matthews, Stephen Voida, Saeed Abdullah, Gavin Doherty, Tanzeem Choudhury, Sangha Im, and Geri Gay. 2015. In Situ Design for Mental Illness: Considering the Pathology of Bipolar Disorder in MHealth Design. In *Proceedings of the 17th International Conference on Human-Computer Interaction with Mobile Devices and Services* (MobileHCI '15), 86–97. https://doi.org/10.1145/2785830.2785866
127. Michael D McCarthy, Sanna J Thompson, and Kerry L Knox. 2012. Use of the Air Force Post-Deployment Health Reassessment for the Identification of Depression and Posttraumatic Stress Disorder: Public Health Implications for Suicide Prevention. *American Journal of Public Health* 102, S1: S60–S65. https://doi.org/10.2105/AJPH.2011.300580
128. Andrew D Miller, Sonali R Mishra, Logan Kendall, Shefali Haldar, Ari H Pollack, and Wanda Pratt. 2016. Partners in Care: Design Considerations for Caregivers and Patients During a Hospital Stay. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing - CSCW '16*, 754–767. https://doi.org/10.1145/2818048.2819983
129. Adam Miner, Eric Kuhn, Julia E. Hoffman, Jason E. Owen, Josef I. Ruzek, and C. Barr Taylor. 2016. Feasibility, acceptability, and potential efficacy of the PTSD coach app: A pilot randomized controlled trial with community trauma survivors. *Psychological Trauma: Theory, Research, Practice, and Policy* 8, 3: 384–392. https://doi.org/10.1037/tra0000092
130. Sonali R Mishra, Shefali Haldar, Ari H Pollack, Logan Kendall, Andrew D Miller, Maher Khelifi, and Wanda Pratt. 2016. "Not Just a Receiver": Understanding Patient Behavior in the Hospital Environment. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems* (CHI '16), 3103–3114. https://doi.org/10.1145/2858036.2858167
131. Sonali R Mishra, Andrew D Miller, Shefali Haldar, Maher Khelifi, Jordan Eschler, Rashmi G Elera, Ari H Pollack, and Wanda Pratt. 2018. Supporting Collaborative Health Tracking in the Hospital: Patients' Perspectives. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems* (CHI '18), 650:1–650:14. https://doi.org/10.1145/3173574.3174224
132. Tracy L Mitzner, Rachel Stuck, Jordan Q Hartley, Jenay M Beer, and Wendy A Rogers. 2017. Acceptance of televideo technology by adults aging with a mobility impairment for health and wellness interventions. *Journal of Rehabilitation and Assistive Technologies Engineering* 4, 4: 1–12. https://doi.org/10.1177/2055668317692755

133. David C. Mohr, Mi Zhang, and Stephen M. Schueller. 2017. Personal Sensing: Understanding Mental Health Using Ubiquitous Sensors and Machine Learning. *Annual Review of Clinical Psychology* 13: 23–47. https://doi.org/10.1146/annurev-clinpsy-032816-044949
134. R. Mojtabai, M. Olfson, N. A. Sampson, R. Jin, B. Druss, P. S. Wang, K. B. Wells, H. A. Pincus, and R. C. Kessler. 2011. Barriers to mental health treatment: Results from the National Comorbidity Survey Replication. *Psychological Medicine* 41, 8: 1751–1761. https://doi.org/10.1017/S0033291710002291
135. Leslie A. Morland, Michelle Raab, Margaret Anne Mackintosh, Craig S. Rosen, Clara E. Dismuke, Carolyn J. Greene, and B. Christopher Frueh. 2013. Telemedicine: A cost-reducing means of delivering psychotherapy to rural combat veterans with PTSD. *Telemedicine and e-Health* 19, 10: 754–759. https://doi.org/10.1089/tmj.2012.0298
136. Sean A Munson. 2017. Rethinking assumptions in the design of health and wellness tracking tools. *interactions*. https://doi.org/10.1145/3168738
137. Elizabeth L Murnane, Tara G Walker, Beck Tench, Stephen Voida, and Jaime Snyder. 2018. Personal Informatics in Interpersonal Contexts: Towards the Design of Technology That Supports the Social Ecologies of Long-Term Mental Health Management. *Proc. ACM Hum.-Comput. Interact.* 2, CSCW: 127:1–127:27. https://doi.org/10.1145/3274396
138. Lisa M Najavits. 2015. The problem of dropout from "gold standard" PTSD therapies. *F1000Prime Reports* 7. https://doi.org/10.12703/p7-43
139. Ada Ng, Rachel Kornfield, Stephen M Schueller, Alyson K Zalta, Michael Brennan, and Madhu Reddy. 2019. Provider Perspectives on Integrating Sensor-Captured Patient-Generated Data in Mental Health Care. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW. https://doi.org/10.1145/3359217
140. Ada Ng, Madhu Reddy, Alyson K. Zalta, and Stephen M. Schueller. 2018. Veterans' perspectives on fitbit use in treatment for post-traumatic stress disorder: An interview study. *JMIR Mental Health* 20, 6. https://doi.org/10.2196/10415
141. Michelle M. Ng, Joseph Firth, Mia Minen, and John Torous. 2019. User engagement in mental health apps: A review of measurement, reporting, and validity. *Psychiatric Services* 70, 7: 538–544. https://doi.org/10.1176/appi.ps.201800519
142. Katie O'Leary, Arpita Bhattacharya, Sean A. Munson, Jacob O. Wobbrock, and Wanda Pratt. 2017. Design opportunities for mental health peer support technologies. In *Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW*, 1470–1484. https://doi.org/10.1145/2998181.2998349
143. Anne Opie. 1998. " Nobody's Asked Me for My View": Users' Empowerment by Multidisciplinary Health Teams. *Qualitative health research* 8, 2: 188–206.
144. Carolyn E Pang, Carman Neustaedter, Bernhard E Riecke, Erick Oduor, and Serena Hillman. 2013. Technology preferences and routines for sharing health information during the treatment of a chronic illness. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems - CHI '13*, 1759. https://doi.org/10.1145/2470654.2466232
145. Mika Pantzar and Minna Ruckenstein. 2017. Living the metrics: Self-tracking and situated objectivity. *Digital health* 3: 2055207617712590. https://doi.org/10.1177/2055207617712590
146. James W Pennebaker and Anna Graybeal. 2001. Patterns of natural language use: Disclosure, personality, and social integration. *Current Directions in Psychological Science* 10, 3: 90–93.

147. Stephen Perconte and Anne Wilson. 1994. Self-report versus observer ratings of distress and pathology in Vietnam veterans with PTSD. *Journal of Traumatic Stress* 7, 1: 129–134. https://doi.org/10.1007/BF02111919

148. R G Winningham PhD and N L Pike. 2007. A cognitive intervention to enhance institutionalized older adults' social support networks and decrease loneliness. *Aging & Mental Health* 11, 6: 716–721. https://doi.org/10.1080/13607860701366228

149. Laura R Pina, Sang-Wha Sien, Teresa Ward, Jason C Yip, Sean A Munson, James Fogarty, and Julie A Kientz. 2017. From Personal Informatics to Family Informatics. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing - CSCW '17*, 2300–2315. https://doi.org/10.1145/2998181.2998362

150. Kyle Possemato, Eric Kuhn, Emily Johnson, Julia E. Hoffman, Jason E. Owen, Nitya Kanuri, Leigha de Stefano, and Emily Brooks. 2016. Using PTSD Coach in primary care with and without clinician support: A pilot randomized controlled trial. *General Hospital Psychiatry* 38: 94–98. https://doi.org/10.1016/j.genhosppsych.2015.09.005

151. Annabel Prins, Paige Ouimette, Rachel Kimerling, Rebecca P Camerond, Daniela S Hugelshofer, Jennifer Shaw-Hegwer, Ann Thrailkill, Fred D Gusman, and Javaid I Sheikh. 2004. The primary care PTSD screen (PC–PTSD): development and operating characteristics. *Primary Care Psychiatry*. https://doi.org/10.1185/135525703125002360

152. Amir M. Rahmani, Jocelyn Lai, Salar Jafarlou, Asal Yunusova, Alex. P. Rivera, Sina Labbaf, Sirui Hu, Arman Anzanpour, Nikil Dutt, Ramesh Jain, and Jessica L. Borelli. 2020. Personal Mental Health Navigator: Harnessing the Power of Data, Personal Models, and Health Cybernetics to Promote Psychological Well-being. Retrieved October 22, 2021 from http://arxiv.org/abs/2012.09131

153. Sheila A. M. Rauch and Barbara O. Rothbaum. 2016. Innovations in exposure therapy for PTSD treatment. *Practice Innovations* 1, 3: 189–196. https://doi.org/10.1037/pri0000027

154. S A Redmond, S L Wilcox, S Campbell, A Kim, K Finney, K Barr, and A M Hassan. 2015. A brief introduction to the military workplace culture. *Work* 50, 1: 9–20. https://doi.org/10.3233/WOR-141987

155. Greg M Reger, Julia Hoffman, David Riggs, Barbara O Rothbaum, Josef Ruzek, Kevin M Holloway, and Eric Kuhn. 2013. The "PE coach" smartphone application: an innovative approach to improving implementation, fidelity, and homework adherence during prolonged exposure. *Psychological services*. https://doi.org/10.1037/a0032774

156. Greg M Reger, Julia Hoffman, David Riggs, Barbara O Rothbaum, Josef Ruzek, Kevin M Holloway, and Eric Kuhn. 2013. The "PE coach" smartphone application: An innovative approach to improving implementation, fidelity, and homework adherence during prolonged exposure. *Psychological Services* 10, 3. https://doi.org/10.1037/a0032774

157. Greg M Reger, Derek Smolenski, Aaron Norr, Andrea Katz, Benjamin Buck, and Barbara O Rothbaum. 2019. Does virtual reality increase emotional engagement during exposure for PTSD? Subjective distress during prolonged and virtual reality exposure therapy. *Journal of Anxiety Disorders* 61. https://doi.org/10.1016/j.janxdis.2018.06.001

158. Andres De Los Reyes and Alan E Kazdin. 2005. Informant Discrepancies in the Assessment of Childhood Psychopathology: A Critical Review, Theoretical Framework, and Recommendations for Further Study. *Psychological Bulletin* 131, 4. https://doi.org/10.1037/0033-2909.131.4.483

159. Carolina Rodriguez-Paras, Kathryn Tippey, Elaine Brown, Farzan Sasangohar, Suzannah Creech, Hye-Chung Kum, Mark Lawley, and Justin K Benzer. 2017. Posttraumatic Stress

Disorder and Mobile Health: App Investigation and Scoping Literature Review. *JMIR mHealth and uHealth* 5, 10. https://doi.org/10.2196/mhealth.7318

160. C S Rosen, M M Matthieu, S Wiltsey Stirman, J M Cook, S Landes, N C Bernardy, K M Chard, J Crowley, A Eftekhari, E P Finley, and et al. 2016. A Review of Studies on the System-Wide Implementation of Evidence-Based Psychotherapies for Posttraumatic Stress Disorder in the Veterans Health Administration. *Administration and Policy in Mental Health and Mental Health Services Research* 43, 6: 957–977. https://doi.org/10.1007/s10488-016-0755-0
161. Barbara Olasov Rothbaum and Ann C Schwartz. 2002. Exposure Therapy for Posttraumatic Stress Disorder. *American Journal of Psychotherapy* 56, 1: 59–75. https://doi.org/10.1176/appi.psychotherapy.2002.56.1.59
162. Barbara Olasov Rothbaum and Ann C Schwartz. 2002. Exposure Therapy for Posttraumatic Stress Disorder. *American Journal of Psychotherapy* 56, 1: 59–75. https://doi.org/10.1176/appi.psychotherapy.2002.56.1.59
163. Larry and Alarcon Renato and Ready David and Shahar Fran and Graap Ken and Pair Jarrel and Hebert Philip and Gotz Dave and Wills Brian and Baltzell David Rothbaum Barbara Olasov and Hodges. 1999. Virtual Reality Exposure Therapy for PTSD Vietnam Veterans: A Case Study. *Journal of Traumatic Stress* 12, 2: 263–271. https://doi.org/10.1023/A:1024772308758
164. Larry and Alarcon Renato and Ready David and Shahar Fran and Graap Ken and Pair Jarrel and Hebert Philip and Gotz Dave and Wills Brian and Baltzell David Rothbaum Barbara Olasov and Hodges. 1999. Virtual Reality Exposure Therapy for PTSD Vietnam Veterans: A Case Study. *Journal of Traumatic Stress* 12, 2: 263–271. https://doi.org/10.1023/A:1024772308758
165. Nicolas Rüsch, Matthias C Angermeyer, and Patrick W Corrigan. 2005. Mental illness stigma: Concepts, consequences, and initiatives to reduce stigma. *European Psychiatry*. https://doi.org/10.1016/j.eurpsy.2005.04.004
166. Samiha Samrose, Ru Zhao, Jeffery White, Vivian Li, Luis Nova, Yichen Lu, Mohammad Rafayet Ali, and Mohammed Ehsan Hoque. 2018. CoCo: Collaboration Coach for Understanding Team Dynamics during Video Conferencing. *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies* 1, 4: 160.
167. Frederic J Sautter, Shirley M Glynn, Karin E Thompson, Laurel Franklin, and Xiaotong Han. 2009. A Couple-Based Approach to the Reduction of PTSD Avoidance Symptoms: Preliminary Findings. *Journal of Marital and Family Therapy* 35, 3: 343–349. https://doi.org/https://doi.org/10.1111/j.1752-0606.2009.00125.x
168. Elaine Schertz, Hue Watson, Ashok Krishna, Andrew Sherrill, Hayley Evans, and Rosa I. Arriaga. 2019. Bridging the Gap: Creating a Clinician-Facing Dashboard for PTSD. In *Lecture Notes in Computer Science (including subseries Lecture Notes in Artificial Intelligence and Lecture Notes in Bioinformatics)*, 224–233. https://doi.org/10.1007/978-3-030-29381-9_14
169. Rebecca Schnall, Hwayoung Cho, and Jianfang Liu. 2018. Health information technology usability evaluation scale (Health-ITUES) for usability assessment of mobile health technology: Validation study. *JMIR mHealth and uHealth* 6, 1: e8851. https://doi.org/10.2196/mhealth.8851

170. Paula P Schnurr and Bonnie L Green. 2004. *Trauma and health: Physical health consequences of exposure to extreme stress.* Washington American Psychological Association.
171. Paula P Schnurr and Bonnie L Green. 2004. *Trauma and health: Physical health consequences of exposure to extreme stress.* American Psychological Association.
172. Georg Schomerus and Matthias C Angermeyer. 2008. Stigma and its impact on help-seeking for mental disorders: What do we know? *Epidemiologia e Psichiatria Sociale*. https://doi.org/10.1017/S1121189X00002669
173. Jessica Schroeder, Jane Hoffswell, Chia Fang Chung, James Fogarty, Sean Munson, and Jasmine Zia. 2017. Supporting patient-provider collaboration to identify individual triggers using food and symptom journals. In *Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW*, 1726–1739. https://doi.org/10.1145/2998181.2998276
174. Bryan Semaan, Lauren M Britton, and Bryan Dosono. 2017. Military Masculinity and the Travails of Transitioning. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing - CSCW '17*, 387–403. https://doi.org/10.1145/2998181.2998221
175. Bryan C Semaan, Lauren M Britton, and Bryan Dosono. 2016. Transition Resilience with ICTs. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems - CHI '16*, 2882–2894. https://doi.org/10.1145/2858036.285thettdah8109
176. Aviv Shachak and Shmuel Reis. 2009. The impact of electronic medical records on patient-doctor communication during consultation: A narrative literature review. *Journal of Evaluation in Clinical Practice* 15, 4: 641–649. https://doi.org/10.1111/j.1365-2753.2008.01065.x
177. Andrew M Sherrill, Jessica R Goodnight, Mark S Burton, and Barbara O Rothbaum. 2020. Use of Virtual Reality Exposure Therapy for Anxiety-and Trauma-Related Disorders. In *Technology and Mental Health*. Routledge, 75–91.
178. Andrew M. Sherrill, Alex O. Rothbaum, Lauren B. McSweeney, and Barbara O. Rothbaum. 2019. Virtual reality exposure therapy for posttraumatic stress disorder. *Psychiatric Annals* 49, 8: 343–347. https://doi.org/10.3928/00485713-20190716-02
179. Brian Shiner, Leonard W D'Avolio, Thien M Nguyen, Maha H Zayed, Yinong Young-Xu, Rani A Desai, Paula P Schnurr, Louis D Fiore, and Bradley v Watts. 2012. Measuring Use of Evidence Based Psychotherapy for Posttraumatic Stress Disorder. *Administration and Policy in Mental Health and Mental Health Services Research* 40: 311–318.
180. Marit Sijbrandij, Ivo Kunovski, and Pim Cuijpers. 2016. EFFECTIVENESS OF INTERNET-DELIVERED COGNITIVE BEHAVIORAL THERAPY FOR POSTTRAUMATIC STRESS DISORDER: A SYSTEMATIC REVIEW AND META-ANALYSIS. *Depression and Anxiety 33*, 783–791. https://doi.org/10.1002/da.22533
181. Thor Jarle J Skinstad and Babak A Farshchian. 2016. Empowerment or Concealed Compliance? A Review of Literature on Mobile ICT Solutions for Patient Empowerment. In *Proceedings of the 9th ACM International Conference on PErvasive Technologies Related to Assistive Environments* (PETRA '16). https://doi.org/10.1145/2910674.2910710
182. Thor Jarle J Skinstad and Babak A Farshchian. 2016. Empowerment or concealed compliance?: A review of literature on mobile ICT solutions for patient empowerment. In

*Proceedings of the 9th ACM International Conference on PErvasive Technologies Related to Assistive Environments*, 54.

183. Daniel W. Smith, B. Christopher Frueh, Craig N. Sawchuk, and Michael R. Johnson. 1999. Relationship between symptom over-reporting and pre- and post-combat trauma history in veterans evaluated for PTSD. *Depression and Anxiety* 10, 3: 119–124. https://doi.org/10.1002/(SICI)1520-6394(1999)10:3<119::AID-DA5>3.0.CO;2-K
184. V A Web Mobile Solutions. 2019. VA DoD Veteran Link. *VA Mobile*. Retrieved from https://mobile.va.gov/app/va-dod-veteran-link
185. Tracy Stecker, Brian Shiner, Bradley v. Watts, Meissa Jones, and Kenneth R. Conner. 2013. Treatment-seeking barriers for veterans of the iraq and afghanistan conflicts who screen positive for PTSD. *Psychiatric Services* 64, 3: 280–283. https://doi.org/10.1176/appi.ps.001372012
186. Cristiano Storni. 2010. Multiple Forms of Appropriation in Self-Monitoring Technology: Reflections on the Role of Evaluation in Future Self-Care. *International Journal of Human–Computer Interaction* 26, 5: 537–561. https://doi.org/10.1080/10447311003720001
187. Cristiano Storni. 2010. Multiple forms of appropriation in self-monitoring technology: Reflections on the role of evaluation in future self-care. *Intl. Journal of Human–Computer Interaction* 26, 5: 537–561.
188. Colm Sweeney, Courtney Potts, Edel Ennis, Raymond Bond, Maurice D Mulvenna, Siobhan O'neill, Martin Malcolm, Lauri Kuosmanen, Catrine Kostenius, Alex Vakaloudis, Gavin Mcconvey, Robin Turkington, David Hanna, Heidi Nieminen, Anna-Kaisa Vartiainen, Alison Robertson, and Michael F Mctear. 2021. Can Chatbots Help Support a Person's Mental Health? Perceptions and Views from Mental Healthcare Professionals and Experts. *ACM Trans. Comput. Healthcare* 2, 3. https://doi.org/10.1145/3453175
189. Charles H Tardy. 1985. Social support measurement. *American journal of community psychology* 13, 2: 187.
190. Matthieu Tixier and Myriam Lewkowicz. 2015. Looking for respite and support: Technological opportunities for spousal caregivers. In *Proceedings of the 33rd annual ACM conference on human factors in computing systems*, 1155–1158.
191. John Torous, Erin E. Michalak, and Heather L. O'Brien. 2020. Digital Health and Engagement - Looking behind the Measures and Methods. *JAMA Network Open 3*, e2010918–e2010918. https://doi.org/10.1001/jamanetworkopen.2020.10918
192. Emanuele Torri, Oscar Mayora, Jesus Cobo, and Diego Palao. 2015. Requirements Identification for the Development of a Design Involving Adaptive ICTs for Supporting Bipolar Disorder Treatment in Different Healthcare Contexts. In *Proceedings of the 9th International Conference on Pervasive Computing Technologies for Healthcare* (PervasiveHealth '15), 272–276.
193. David Turgoose, Rachel Ashwick, and Dominic Murphy. 2018. Systematic review of lessons learned from delivering tele-therapy to veterans with post-traumatic stress disorder. *Journal of Telemedicine and Telecare* 24, 9: 575–585. https://doi.org/10.1177/1357633X17730443
194. R Jay Turner and Robyn Lewis Brown. 2010. Social support and mental health. *A handbook for the study of mental health: Social contexts, theories, and systems* 2: 200–212.

195. U.S. Department of Veterans Affairs. 2014. Substance Abuse in Veterans - PTSD: National Center for PTSD.
196. User Experience Magazine. 2009. Determining What Individual SUS Scores Mean: Adding an Adjective Rating ScaleJUS.
197. Debra VanderVoort. 1999. Quality of Social Support in Mental and Physical Health. *Current Psychology* 18, 2: 205–222. https://doi.org/10.1007/s12144-999-1029-8
198. John Vines, Roisin McNaney, Rachel Clarke, Stephen Lindsay, John McCarthy, Steve Howard, Mario Romero, and Jayne Wallace. 2013. Designing for- and with- vulnerable people. In *CHI '13 Extended Abstracts on Human Factors in Computing Systems on - CHI EA '13*. https://doi.org/10.1145/2468356.2479654
199. John Vines, Róisín McNaney, Stephen Lindsay, Jayne Wallace, and John McCarthy. 2014. Special topic: Designing for and with vulnerable people. *interactions*. https://doi.org/10.1145/2543490
200. Stephen Voida, Mark Matthews, Saeed Adbullah, Mengxi Chi, Matthew Green, Won Jun Jang, Donald Hu, John Weinrich, Prashama Patil, Mashfiqui Rabbi, Tauhidur Rahman, Geri Gay, Ellen Frank, and Tanzeem Choudhuray. 2013. Moodrhythm: Tracking and supporting daily rhythms. In *UbiComp 2013 Adjunct - Adjunct Publication of the 2013 ACM Conference on Ubiquitous Computing*, 67–70. https://doi.org/10.1145/2494091.2494111
201. Rui Wang, Min S H Aung, Saeed Abdullah, Rachel Brian, Andrew T Campbell, Tanzeem Choudhury, Marta Hauser, John Kane, Michael Merrill, Emily A Scherer, Vincent W S Tseng, and Dror Ben-Zeev. 2016. CrossCheck: Toward Passive Sensing and Detection of Mental Health Changes in People with Schizophrenia. In *Proceedings of the 2016 ACM International Joint Conference on Pervasive and Ubiquitous Computing* (UbiComp '16), 886–897. https://doi.org/10.1145/2971648.2971740
202. Rui Wang, Alex Dasilva, Jeremy F Huckins, William M Kelley, Todd F Heatherton, Andrew T Campbell, Weichen Wang, ; Todd, and F Heatherton. 2018. Tracking Depression Dynamics in College Students Using Mobile Phone and Wearable Sensing. *Proc. ACM Interact. Mob. Wearable Ubiquitous Technol. 2, 1, Article* 43, 1: 43. https://doi.org/10.1145/3191775
203. Weichen Wang, Shayan Mirjafari, Gabriella Harari, Dror Ben-Zeev, Rachel Brian, Tanzeem Choudhury, Marta Hauser, John Kane, Kizito Masaba, Subigya Nepal, Akane Sano, Emily Scherer, Vincent Tseng, Rui Wang, Hongyi Wen, Jialing Wu, and Andrew Campbell. 2020. Social Sensing: Assessing Social Functioning of Patients Living with Schizophrenia using Mobile Phone Sensing. In *Conference on Human Factors in Computing Systems - Proceedings*, 1–15. https://doi.org/10.1145/3313831.3376855
204. Zhiyun Wang, Jianping Wang, and Andreas Maercker. 2013. Chinese my trauma recovery, a web-based intervention for traumatized persons in two parallel samples: Randomized controlled trial. *Journal of Medical Internet Research* 15, 9. https://doi.org/10.2196/jmir.2690
205. Washington University in St. Louis. 2008. Growing Problem For Veterans: Domestic Violence.
206. Mary Edwards Wertsch. 1991. *Military brats: Legacies of childhood inside the fortress*. Brightwell Publishing.
207. Peter West, Max van Kleek, Richard Giordano, Mark J Weal, and Nigel Shadbolt. 2018. Common Barriers to the Use of Patient-Generated Data Across Clinical Settings. In

*Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems* (CHI '18), 484:1–484:13. https://doi.org/10.1145/3173574.3174058

208. Julia M Whealin, Emily C Jenchura, Ava C Wong, and Donna M Zulman. 2016. How veterans with post-traumatic stress disorder and comorbid health conditions utilize ehealth to manage their health care needs: a mixed-methods analysis. *Journal of medical Internet research* 18, 10: e280.
209. Rena R Wing and Robert W Jeffery. 1999. Benefits of recruiting participants with friends and increasing social support for weight loss and maintenance. *Journal of Consulting and Clinical Psychology* 67, 1: 132–138. https://doi.org/10.1037/0022-006X.67.1.132
210. Langdon Winner. 1980. Do artifacts have politics? *Daedalus*: 121–136.
211. Langdon Winner. 1980. Do artifacts have politics? *Daedalus*: 121–136.
212. Naomi Yamashita, Hideaki Kuzuoka, Keiji Hirata, Takashi Kudo, Eiji Aramaki, and Kazuki Hattori. 2017. Changing Moods: How Manual Tracking by Family Caregivers Improves Caring and Family Communication. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (CHI '17), 158–169. https://doi.org/10.1145/3025453.3025843
213. Rachel Yehuda, Lisa Tischler, Julia A Golier, Robert Grossman, Sarah R Brand, Shira Kaufman, and Philip D Harvey. 2006. Longitudinal Assessment of Cognitive Performance in Holocaust Survivors with and without PTSD. *Biological Psychiatry* 60, 7. https://doi.org/10.1016/j.biopsych.2006.03.069
214. Langxuan Yin, Lazlo Ring, and Timothy Bickmore. 2012. Using an Interactive Visual Novel to Promote Patient Empowerment Through Engagement. In *Proceedings of the International Conference on the Foundations of Digital Games* (FDG '12), 41–48. https://doi.org/10.1145/2282338.2282351
215. Renwen Zhang, Kathryn E. Ringland, Melina Paan, David C. Mohr, and Madhu Reddy. 2021. Designing for Emotional Well-Being: Integrating Persuasion and Customization into Mental Health Technologies. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. Association for Computing Machinery, New York, NY, USA. Retrieved from https://doi.org/10.1145/3411764.3445771
216. Leming Zhou, Jie Bao, I. Made Agus Setiawan, Andi Saptono, and Bambang Parmanto. 2019. The mhealth app usability questionnaire (MAUQ): Development and validation study. *JMIR mHealth and uHealth* 7, 4: e11500. https://doi.org/10.2196/11500
217. Lori A Zoellner, Norah C Feeny, Joyce N Bittinger, Michele A Bedard-Gilligan, David M Slagle, Loren M Post, and Jessica A Chen. 2011. Teaching trauma-focused exposure therapy for PTSD: Critical clinical lessons for novice exposure therapists. *Psychological Trauma: Theory, Research, Practice, and Policy* 3: 300–308.
218. 2014. U.S. Department of Veterans Affairs, ``Study explores reasons why Veterans seek or don't seek PTSD care''. *Office of Research & Development*. Retrieved from https://www.research.va.gov/currents/spring2014/spring2014-25.cfm
219. 2018. Clinical Practice Guideline for the Treatment of Posttraumatic Stress Disorder (PTSD). *American Psychological Association*. Retrieved from https://www.apa.org/ptsd-guideline
220. 2018. Traumatic Brain Injury and PTSD: Focus on Veterans. *Treatment of PTSD - PTSD: National Center for PTSD*. Retrieved from https://www.ptsd.va.gov/professional/treat/cooccurring/tbi_ptsd_vets.asp

221. 2018. U.S. Department of Veterans Affairs, ``How Common is PTSD in Veterans? - PTSD: National Center for PTSD''. *Treatment of PTSD - PTSD: National Center for PTSD*. Retrieved from https://www.ptsd.va.gov/understand/common/common_veterans.asp
222. 2018. U.S. Department of Veterans Affairs, ``PTSD and Substance Abuse in Veterans - PTSD: National Center for PTSD''. *Treatment of PTSD - PTSD: National Center for PTSD*. Retrieved from http://www.ptsd.va.gov/public/problems/ptsd_substance_abuse_veterans.asp
223. 2019. Snapchat. Retrieved from http://www.snapchat.com/
224. How Common is PTSD in Veterans? - PTSD: National Center for PTSD. Retrieved October 21, 2021 from https://www.ptsd.va.gov/understand/common/common_veterans.asp
225. Patient Engagement | Health Affairs. Retrieved October 21, 2021 from https://www.healthaffairs.org/do/10.1377/hpb20130214.898775/full/
226. The Coding Manual for Qualitative Researchers | SAGE Publications Ltd. Retrieved October 23, 2021 from https://uk.sagepub.com/en-gb/eur/the-coding-manual-for-qualitative-researchers/book243616